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ABSTRACT

This manual provides basic information for teachers and others who are interested in helping children learn about different disabilities. Each section includes information about a particular disability and answers questions that children might have about the disability. The first section addresses visual impairments and contains information on signs of eye trouble, causes of visual impairments, and visual aids. Section 2 focuses on hearing impairments and explains different types of hearing loss, communication methods, and hearing aids. Physical disabilities are addressed in Section 3, including cerebral palsy, spina bifida, spinal cord injury, muscular dystrophy, juvenile rheumatoid arthritis, multiple sclerosis, brittle bone disease, and amputation. Section 4 discusses mental retardation, including causes of mental retardation and teaching methods. Different types of learning disabilities are addressed in Section 5. Sections 6, 7, 8, and 9 provide information on speech impairments, autism, other health impairments (cystic fibrosis, juvenile diabetes, epilepsy, and attention-deficit/hyperactivity disorder), and multiple disabilities. The last section reviews federal laws that affect children with disabilities. Each disability section includes simulation exercises and a list of books, videos, and organizations that provide further information about the particular disability. A list of parent resource centers is provided. (CR)

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A Guidebook for Families and Educators

Second Edition

PACER CENTER

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Disability Awareness:

A Guidebook for Families and Educators

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Introduction

The Individuals with Disabilities Act (IDEA) ensures that many children with disabilities can be educated along with their peers who do not have disabilities. Educating children with disabilities in the regular classroom requires some preparation. While children with disabilities and their teachers may receive preparation, very little may be done to assist other students in learning about disabilities and relating to their classmates and others who have disabilities. Children frequently have fears about disabilities, questions and comments about aids and appliances, and apprehensions about a child who may seem somewhat different.

PACER Center, Inc., has developed this manual to be used as a resource guide by teachers and others who are interested in helping children learn about disabilities.

Disability Awareness: A Guidebook for Families and Educators provides basic information about many disabilities. The resource sections point readers to books, videos, and organizations that provide further information about particular disabilities. The danger of summaries like these is that some information is unintentionally minimized or omitted. Please keep in mind that this manual is intended not as a detailed authority but as an introduction to many disabilities and source of ideas on classroom activities.

Summaries of IDEA and several other important laws offer a brief overview of the legal rights afforded to children with disabilities and their families. The process of identifying children with disabilities, evaluating each child's needs, and providing appropriate programs to meet those needs is extremely important. We hope this information will provide encouragement to all individuals who are interested in children.

Visual Impairments

IDEA regulations define visual impairments as "impairment in vision that, even with correction, adversely affects a child's educational performance." The term includes not only children who are blind but also those with partial sight.

Children with vision impairments may have trouble learning in a regular classroom because their limited sight interferes with acquiring information or interacting with the classroom environment. They may have difficulty using textbooks, worksheets, chalkboards, computers, or other common learning tools. Their sight may be affected by environmental factors that cannot be controlled, such as lighting, contrast, weather, color, or movement. Or they may experience visual fatigue that affects their ability to keep pace with other students in the classroom. For these reasons, special modifications and adaptations are needed to help students with visual impairments learn in the classroom.

Nationwide, visual impairments affect approximately one student in a thousand, and approximately three out of ten of those students must use alternate methods of learning.

The National Federation of the Blind (NFB) estimates that about 750,000 people in the U.S. are blind, and 50,000 more will become blind each year. Studies show that only AIDS and cancer are feared more than blindness. According to NFB, "Blindness need not be the tragedy that it is generally thought to be. The real problem of blindness is not the loss of eyesight, but the misunderstanding and lack of information which exist."

What is vision impairment?

Vision disorders fall into three basic categories:

1. malfunctions that can be corrected with lenses
2. impairments that affect sight even with corrective lenses
3. severe impairments that require alternative methods of reading and travel

All parts of the eye must work correctly to provide the best possible vision. Unfortunately, the eye is so complex, that even slight variations can cause vision problems. The most common problems are the refractive errors: *myopia* or nearsightedness, *hyperopia* or farsightedness, and *astigmatism*. Most cases are correctable by glasses or contacts.

Vision is usually measured using the Snellen Eye Test and reported as a fraction. Normal vision is 20/20. A person is considered to have 20/70 vision if, when standing 20 feet from a Snellen Chart, he or she can only identify the symbol that someone with normal eyesight would be able to identify at 70 feet or more.

The terms *visually impaired, low vision*, and *partially sighted* refer to a loss of vision in the range of 20/60 to 20/200 with correction. To these people, objects may look dim, blurred, or out of focus. Some people have tunnel vision—they lack peripheral vision or see only those things directly in the center of their line of vision. Children who are partially sighted can still use their vision sometimes when aided with magnifiers or similar devices.

The legal definition of *blind* includes a "visual acuity of 20/200 or less in the better eye after correction, or severely-reduced peripheral vision (tunnel vision)." This includes not only people who are totally without vision (that is, unable to distinguish light from dark or with no perception) but also those who have some vision in one or both eyes. Ninety percent of people referred to as blind do have some remaining vision.

People who are blind may rely on hearing and touch as their chief means of learning and use alternative techniques to read, write, or travel. They may use Braille, white canes or guide dogs, aids and appliances marked in Braille, talking books, and other methods to gain information that people with sight gain through their vision.

Vision impairment, in and of itself, does not affect intelligence or hearing and does not leave people helpless or dependent. Using alternative techniques to learn about the world around them, people who are blind or visually impaired can lead independent lives.

Signs of possible eye trouble in children

Behavior

- rubs eyes excessively
- shuts or covers one eye, tilts head, or thrusts head forward
- has difficulty in reading, holds work close to eyes
- blinks more than usual or becomes irritable when doing close work
- unable to see clearly at a distance
- squinting or frowning

Appearance

- crossed eyes
- red-rimmed, encrusted, or swollen eyelids
- inflamed or watery eyes
- recurring styes
- nystagmus [involuntary movement of the eye]

Complaints

- eyes itch, burn, or feel scratchy
- cannot see well
- dizziness, headaches, or nausea following close eye work
- blurred or double vision

Source: National Society to Prevent Blindness, New York, NY 10016. Used with permission.

Causes of partial sight or blindness

Some vision impairments and their causes are listed below:

Amblyopia. This dimness of vision without any apparent diseases of the eye is usually the result of strabismus, not using an eye because of a muscle problem.

Cataracts. Cataracts are a clouding of the lens that reduces the amount of light the retina receives. They generally do not affect the field of vision but result in hazy sight, especially in glaring light. Cataracts most often occur in only one eye and can progress until they interfere with vision. They can often be surgically removed and corrective lenses or contact lenses can be worn. The chance of perfect vision depends on other abnormalities also associated with the cataracts. Cataracts in children are often congenital.

Diabetes. This disorder involving defective metabolism of glucose and other substances may result in degenerating eyesight. Print may appear distorted or blurred. Many diabetics also develop cataracts, resulting in hazy and distorted vision.

Glaucoma. With glaucoma, the normal fluid in the eye does not drain properly, causing increased pressure within the eye. This pressure can damage the optic nerve, resulting in severe loss of sight or tunnel vision. Print may appear to lack contrast. Glaucoma, which is usually detected by pressure checks during routine eye exams, can be treated.

Maternal syphilis. This cause of blindness has become uncommon now that many states require silver nitrate eye drops to be given to newborns immediately after birth.

Retinopathy of Prematurity (ROP). With this disease of the retina, a mass of scar tissue forms in the back of the lens. ROP affects both eyes and can cause a complete loss of sight. ROP most often affects premature babies who must receive a high concentration of oxygen in order to survive.

Retinitis pigmentosa. This heredity disease causes gradual degeneration of the pigmented layer of the retina. It leads to severe loss of peripheral vision. The reading area is reduced, although some letters in the center may be clear.

Retinal detachment. With this eye condition, a hole in the retina allows fluid to leak behind the retina and push it off the back of the eye. Vision can be lost, but surgery can correct the problem.

Trachoma. This infectious disease of the eye causes scarring of the cornea, which reduces vision to light perception only.

Some children with eye problems may have other impairments caused by a specific disease or disorder such as prenatal German measles (rubella) or malignancies such as retinal blastoma.

Aids and appliances

People with limited vision can travel independently, read, and do most of the ordinary tasks of daily living when they use appropriate aids and appliances.

Travel aids

Today most people who are blind use a white cane to gain information about the area in which they are walking. Using a cane properly, people who are blind can travel on their own wherever they need to go.

The cane is straight and usually made of metal or fiberglass with nonskid padding at the top for gripping. Rigid and nonrigid canes (those with folding, telescopic, or screw-together pieces) are available with metal, nylon, and light-sensitive tips. Adults who are blind use canes about armpit-height, four or five feet long depending on their height and stride. Canes for children should also vary according to their height. People who are blind tap the cane back and forth in an arc about one inch outside the widest part of their body on either side.

Many areas have teachers trained to help people who are blind learn how to travel in their community, cross streets, use a Braille compass, negotiate traffic, ride public transportation, and learn other necessary travel skills. Most people who are blind keep their white canes with them the majority of the time when they are outside their own homes. While in class or at a desk, they may lay their canes on the floor nearby or in another convenient spot, or keep them folded in a purse, pocket, or backpack.

A specially trained guide dog can also be used for travel by people who are 18 years of age or older. The dogs are trained at a school. The owner is also trained in techniques of using a guide dog. The dog in a harness walks slightly ahead of the person who is blind so the person can learn from the movement of the dog about steps and other obstacles. The person who is blind directs the dog, but the dog is trained to disobey a particular command if that movement would endanger his master's life (e.g., walking in front of a car).

Guide dogs do require care and can become sick or injured just as any animal might. Many people who are blind feel that a cane can do the same things a dog can without the associated problems of animal care.

Learning aids

Many alternative methods of learning have been developed for people without enough sight to use visual methods:

Braille. A fifteen-year-old French boy, Louis Braille, who was blind, developed this system for reading and writing. He based his system on a secret military code that let soldiers communicate in writing after dark.

Braille, which is read with the fingertips, is composed of raised dots arranged in various combinations to represent single letters, phonetic sounds, or entire words. It's not another language but a code system that can represent languages like English and Spanish. The code can be written with a Brailler (similar to a typewriter) or with a slate and stylus. The pointed stylus is used to punch dots into heavy paper using a Braille slate as a guide.

Louis spent nine years improving and refining the system so that each letter or phonetic sound could be "read" by the human fingertip. The basic "Braille cell" has two rows of three dots each. Each letter or number is composed of a certain combination of these dots. Some common words and abbreviations are written in Braille contractions.

There are three grades of Braille.

- **Grade one** is the most basic. It includes all the letters in most words and special symbols that indicate capital letters and punctuation.
- **Grade two** is the most common form of Braille used in published materials. It is a shortened form with about 300 contractions. It can be read faster and requires less space.
- **Grade three** Braille has even more contractions and is used mainly for personal notetaking.

Nemeth Code is a mathematical notation based on Braille that helps people who are blind express technical and numerical information more efficiently.

It takes some practice to become a good reader of Braille, as it does to read print. The learning process is somewhat the same. Beginning readers are taught to associate a certain symbol with a letter sound or a word meaning. The difference is that in Braille, the symbol is tactile rather than visual.

Because Braille writing takes up more space on a page than conventional print, Braille books are large and quite expensive to produce. Most states (including Minnesota) have libraries of Braille material that can be borrowed by people who are blind. By U.S. law, books for people who are blind can be mailed free of charge.

Twin vision books. Available with both Braille and print words and pictures in print and raised form. People can read them to children who are either sighted or blind.

Auditory materials. Many people who are blind, especially those who have become blind later in life, rely solely on auditory materials. Other people use them in addition to Braille materials.

Here is a brief description of some of the many materials currently available:

- Talking books—special audiotapes that can be adjusted to play at a rate faster than normal speech and require special equipment to use. The National Library Service for the Blind and Physically Handicapped (NLS) makes tapes of books, magazines, and other reading materials available to state libraries. State libraries provide the materials and equipment free of charge to eligible state residents.
- Audiobooks or books on tape—Popular titles are available from the library and bookstores to be used on a normal cassette player.
- Talking records—long-playing records of printed materials.
- Talking calculators.
- Talking watches and clocks.
- Optical character scanners—electronic devices that scan a printed page and produce an audible reading of the material.
- Digital talking books—As technology changes, the NLS is planning a digitally based system of providing print materials to people who are unable to read standard print publications because of a physical disability.

Technology. Computers can be adapted for use by those who are blind. Voice synthesizers provide spoken rather than printed readouts. Large screens or large character displays can make it easier for people with impaired vision to read from the screen. Other adaptations include Braille printers that can hook up to a computer, portable computer keyboards, talking software, Braille keyboards, or Braille 'n' Print. There are pocket Braillers, portable Braillers, and Braille 'n' Speak units, as well as large print computer software too. Each of these devices has particular functions that fit the needs, skill abilities, and the setting of the person who is blind.

Opticon. This device translates printed material into electrical impulses that can be read with the fingertips. The reader passes a scanner over a regular printed page with one hand and feels the electrical pattern (which is not Braille) with the other hand.

Readers. Many older students who are blind, particularly at the college level, use volunteer or paid readers to help them with their reading assignments.

Low-vision aids. Such devices as closed-circuit television that enlarges print and various magnifiers are used by people with limited vision. Depending upon the specific visual disability and its effect on functional vision, these aids help some people, but not everyone. Often, these aids are useful in combination with Braille or tapes. Some textbooks are also produced in large-print editions for primary and secondary students. However, they are not usually available at the postsecondary level because of the expense of production.

Watches, clocks, games, and cooking equipment are also available with large print.

Daily living aids

There is a wealth of adapted materials used by people who are blind, and many people with visual impairments create their own adaptations to meet their individual needs. Catalogs of materials for the blind list such items. For instance, the Products Catalog for People with Visual Problems is available from the American Foundation for the Blind, Consumer Products Dept., 15 W. 16th St., New York, NY 1001, or call toll-free 1-800-232-5463 or (1-800-AFBLIND).

Here's a sample of the kinds of materials available:

- talking thermometer
- tactile watches (with dots), talking watches, and low-vision watches (with large numerals)
- Braille Scrabble, Monopoly, playing cards
- tactile checkers (recessed squares on board)
- chessboard with raised black squares drilled for pegged chess pieces
- dominoes with raised black dots
- magnifier for sewing machine (attaches to needle area)
- kitchen aids such as pie cutting guides and electronic liquid level indicators
- check and envelope guides for writing
- carpentry tools marked in Braille

Recreational adaptations

People who are blind ride tandem bikes, ski, swim, jog, bowl, play baseball and other games, often with only minor adaptations. These adaptations are usually individually tailored to the needs of the particular person. Children with blindness usually play with playmates who are sighted and make unique adaptations in order to participate. Children who are blind can enjoy many games if participants simply explain what they are doing or what is happening.

Beep baseball is played with a large baseball with an electronic beep and two bases that make a buzzing sound. A pitcher who is sighted throws the beeping ball to the batter who is blind. If the batter hits the beeping ball out into the field, he or she runs to whichever base is making a sound (first base or third base). When the ball is hit, the five fielders who are blind drop to their knees and block the ball with their bodies. If the batter makes it to the buzzing base before the fielders pick up the ball, he or she gets a point. But if fielders pick up the beeping ball before the batter makes it to the buzzing base, he or she is out.

Balls with bells inside are available in several sizes.

Basketball can be adapted in unique ways. A regulation ball is easily heard, and baskets can be identified with different noises.

Other activities. Many people who are blind cross-country ski with a companion who is sighted. There are special guide programs at downhill ski areas. Bowlers who are blind can use a guide rail. Some people who are blind roller-skate, ride horses, swim, or ride tandem bicycles with a sighted friend. Children can ride regular tricycles with supervision.

Educational methods

Most students who are blind receive instruction in reading and writing Braille from a vision teacher at school. These teachers often travel to several schools. The vision teacher obtains the child's classroom materials in Braille or on tape, and the student learns Braille just as children who are sighted learn print. Many students who are blind learn to use a special keyboard so a teacher who is sighted can easily correct their work. The input is Braille; the output is print.

Questions children ask about vision impairment

Gina has been blind from birth. She has congenital cataracts. She carries a white cane, wears a Braille watch, and has Braille books and games. She enjoys playing the drums and riding a tandem bike with her friends.

Q. Do you always use your white cane?

A. No, only when I'm going to a place I don't know well. I don't use it at home most of the time, because I know where everything is! In school, although I know where things are, I like to have my cane with me in case teachers or kids move things around.

Q. If you lose your white cane or something else, how do you find it again?

A. I feel around the places where I usually leave it, or I try real hard to remember where I left it. Otherwise, I ask someone for help.

Q. Will you have that white cane all your life?

A. As long as I want it. But as I grow, I get new ones, because a cane has to be the right size for my height. There are fold-up canes, sectional canes, and fiberglass canes that are right for my travel needs, too.

Q. Will you ever get a Seeing Eye dog?

A. Maybe. I have to be 18 years old to have a guide dog. When you get a guide dog, you have to go to school to learn how to use and care for the dog properly.

Q. How can you tell where food is on your plate?

A. When I was younger, I liked to pretend my plate was like a clock. Mom would put my vegetables at 12:00, potatoes at 3:00, meat at 6:00 because that means it was closest to me, making it easier to cut it. But now that I'm older, I can tell what foods are by their smell and by feeling them with my fork.

Q. How can you pour a glass of juice?

A. I just put my finger over the edge of the glass to tell how full it's getting. We use a certain pitcher at home for orange juice, another for milk, so I can tell by the feel of the pitcher what's inside.

Q. How can you tell what people look like?

A. Well, there are several ways. If they are close friends, I ask to touch their hair and face and then I have some idea. But usually I listen to the voice and imagine what a person looks like. I figure a person who sounds nice must look nice. I also ask people to tell me what they look like.

Q. What sports can you play or what outside activities can you do?

A. I like many different sports. Most can be adapted so I can play, too. I like to ride a tandem bicycle with my brother or friends. Cross-country skiing is fun, and I love to bowl.

Q. Are you scared being blind like I'm scared of the dark?

A. No. I've learned how to get around and how to listen really well, so being blind doesn't scare me.

Q. Do you have hobbies like other kids?

A. Sure. I love to read. I get Braille books through special libraries. I have quite a tape and record collection, and I love to play the drums.

Q. Can you really hear better than other people?

A. No, but I do need to pay better attention to the things I hear, because that is a very important way I learn about things.

Simulation activities for blindness

For many people the idea of being blind is scary. Some cannot imagine how they could accomplish ordinary tasks without seeing. Most people who are blind will tell you that they are not frightened, and that with practice, most tasks become easy. While we believe it is important to help children understand how people who are blind accomplish various tasks, it is important to stress during these experiences that people who are blind are not frightened and do not have extraordinary abilities.

TOUCH AND FEEL BAG

Age level: preschool and primary grades
Equipment: cloth or paper bag, three or four items familiar to children, one or two items not so familiar.
How to play: Seat children in a circle and try these games:

- Put six items in the bag. Name one item and have child find it by feeling. Take it out for all to see. Pass the bag on.
- Put one item in bag. Pass bag around and have each child guess what it is by just feeling.
- Put a very unusual item in the bag. Have one child describe what it feels like and have rest of class guess what it is.

GUESS WHAT THAT IS?

Age level: preschool and elementary
Equipment: a recording of common sounds (like cars honking, animal noises, etc.)
How to play: Tell the children to close their eyes and pretend they are standing on a curb (or in a doorway). Like a person who is blind, each must listen carefully to hear what's going on—what's going by, what animal is there, etc. What would they learn or know from the sounds?

WHAT'S GOING ON?

Age level: elementary
Equipment: television monitor and VCR with videotape
Watch a video with the darkness level adjusted to obscure the action on the screen. Discuss how students think the characters and scenery look. Show the video again without the darkness level adjustment, and compare notes.

WRITING BRAILLE

Age level: elementary
Equipment: a blunt pencil and heavy paper for each participant. A card with the Braille alphabet.
How to play: Ask the children to use the pencil to punch Braille cells into a piece of construction paper. Let the children read each other's notes.

TELL ALL

Age level: elementary
Equipment: none
How to play: Have one student volunteer sit in a central place in the classroom with eyes closed for a few minutes. Ask the child to report what he or she could tell about events during that time.

TRY IT OUT

Age level: all ages
Equipment: aids and appliances used by blind and partially sighted people (e.g., slate and stylus, bell ball, Braille games, Braille books, white cane)
How to play: Let students try equipment used by the blind. A yardstick or umbrella can substitute for a white cane.

TASTE TEST

Age level: **elementary**
Supplies: pairs of related foods such as an apple and a pear; an orange and a grapefruit; two types of soda, graham crackers and vanilla wafers
How to play: Have children try to identify these foods by tasting and smelling only, not by seeing or feeling. Discuss how much they could tell about the foods.

Joyce E. Lindgren, P.H.N., M.P.H., a consultant who deals with family issues related to children with special needs and parent of several children with vision impairment, and Judith Normandin, special education teacher for people who are visually impaired contributed to this chapter.

Resources

Books for children

Alder, David A. *A Picture Book of Helen Keller.* New York: Holiday House, 1992. This is a brief biography of the woman who became both blind and deaf in early childhood, but over came both disabilities through help of a talented teacher. (P)

———. *A Picture Book of Louis Braille.* New York: Holiday House, 1997. After injuring his eye with an awl, Louis went blind and invented a new way for blind people to read and write. (P)

Carrick, Carol. *Melanie.* New York: Clarion books, 1996. In this original fairy tale, Melanie's grandfather goes in search of a reputed healer who can cure his granddaughter's blindness. When he fails to return, Melanie follows and rescues him from a hideous troll. (P)

Davidson, Margaret. *Louis Braille: The Boy Who Invented Books for the Blind.* New York: Scholastic, Inc., 1991. A biography of the boy who invented the code that lets people who are blind read and write. (M, U)

Garfield, James B. *Follow My Leader.* New York: Puffin, 1994. This classic book from the late 1960s has been recently reissued and still touches kids today. Jimmy, blinded in an accident with a firecracker, has to relearn all the things he used to know. (P, M)

Hite, Sid. *The Distance of Hope.* New York: Henry Holt, 1998. Fifteen-year-old Yeshe Anjur, the nearly blind heir to the throne of Padma, undertakes a dangerous journey to far-off Tigistan to find the legendary White Bean Lama who may be able to restore his sight. (U)

Karim, Roberta. *Mandy Sue Day.* New York: Clarion Books, 1994. Using her senses of taste, hearing, touch, and smell, a girl who is blind enjoys a special day on the farm with her horse. (P)

Keats, Ezra Jack. *Apartment 3.* New York: Macmillan, 1986. The story of a young man who is blind and how he makes music. (M, U)

Litchfield, Ada B. *A Cane In Her Hand.* Morton Grove, IL: Albert Whitman & Co., 1987. A young girl finds ways to cope with her failing vision. One of the few books available about a child who is not blind but has a vision impairment, this book shows how Valerie's teacher adapts her lessons, how her friends accept her, and how her cane helps her. (P)

Little, Jean. *Little by Little, A Writer's Education.* New York: Puffin, 1991. Jean Little describes what it is like to grow up nearly blind from birth. With unwavering support and love of her family, she thrived in a world that always told her she would never make it. (M, U)

Little, Jean. *Stars Come Out Within.* New York: Viking, 1991. A continuation of her memoir, *Little by Little,* Jean writes about her struggles with depression and overcoming her physical limitations. (U)

MacLachlan, Patricia. *Through Grandpa's Eyes.* New York: Harper Trophy, 1983. A young boy learns a different way of seeing the world from his grandfather who is blind. (P)

Martin, Jr., Bill and John Archambault. *Knots on a Counting Rope.* New York: Owlet, 1997. This highly recommended book tells the tender story of a Navajo boy and his grandfather, who often describes events from the boy's life. The storytelling is an affirmation of the boy's strength and courage, giving him the confidence to confront his blindness. Also available on audiotape. (P, M)

McDaniel, Lurlene. *I'll Be Seeing You.* New York: Bantam Starfire, 1996. Sixteen-year-old Carley Mattea, scarred by a facial deformity, meets handsome 17-year-old Kyle in the hospital after he is blinded by a chemistry experiment explosion. He's depressed, and Carly tries to help but worries what Kyle will think of her once his bandages are removed. (U)

McKenzie, Ellen Kindt. *Stargone John.* New York: Henry Holt, 1990. First-grader John is so shy and withdrawn that he refuses to learn to read and write. He is punished by his teacher and taunted as "Stargone John" by his classmates. Miss Mants, who is blind, saves him with her patient teaching; he, in turn, rescues her. (P, M)

St. George, Judith. *Dear Dr. Bell—Your Friend, Helen Keller.* New York: Beech Tree, 1993. Follows the parallel lives of Helen Keller and Alexander Graham Bell, who continued to encounter and support each other from that eventful meeting when he recommended she be given a teacher and thus led her to Annie Sullivan. (U)

Taylor, Theodore. *The Cay.* New York: Harcourt Brace, 1995. In this reissue of the acclaimed 1969 classic, Phillip is blinded when a German submarine torpedoes his freighter during World War II. He's shipwrecked on a tiny Caribbean island with Timothy, and old West Indian native.

Taylor, Theodore. *Timothy of the Cay.* San Diego, Hartcourt Brace, 1993. In this long-awaited prequel/sequel to *The Cay* Phillip is rescued and hopes to regain his sight with an operation. Alternate chapters follow the life of Timothy from his days as a young cabin boy. (M, U)

Turk, Ruth. *Ray Charles: Soul Man.* Minneapolis: Lerner Press, 1996. A biography of the popular singer, who became blind as a young boy. (P,M)

Walsh, Jill Paton. *Goldengrove.* New York: Farrar Straus & Giroux, 1985. Expecting the usual carefree and happy summer with her cousin Paul at their grandmother's seaside home, Madge finds this summer to be different from all the others. (M, U)

Whelan, Gloria. *Hannah.* New York: Random House, 1993. In 1887, Hannah, a nine-year-old girl who is blind and wishes she could go to school, is confined to her house, until a new teacher arrives in town and teaches Hannah how to be self-sufficient (P)

Books for adults

Blasch, Bruce B., William R. Wiener, and Richard L. Welsh. *Foundations of Orientation and Mobility.* New York: American Foundation for the Blind, 1997. This textbook was written by renowned experts on mobility.

Corn, Anne, Chris Cowan, and Elaine Moses. *You Seem Like a Regular Kid to Me!* New York: American Foundation for the Blind,1988. An interview with Jane, who tells other children what it's like to be blind. Jane explains how she gets around, takes care of herself, does her schoolwork, spends her leisure time, and even pays for things when she can't see the money.

Corn, Anne, and Iris Martinez. *When You Have a Visually Handicapped Child in Your Classroom: Suggestions for Teachers.* New York: American Foundation for the Blind, 1988. Practical suggestions for the regular classroom teacher whose class includes a student with a visual impairment.

Curran, Eileen. *Just Enough to Know Better: Braille Primer.* Boston: National Braille Press, 1994. A wonderful resource for parents and classroom teachers who want to know "just enough" to be able to help a child who's learning to read and write Braille. Includes exercise sections written in both print and Braille.

Harley, Randall K., Mila B. Truan, and Sanford D. Larhea. *Communication Skills for Visually Impaired Learners: Braille, Print, and Listening Skills for Students Who Are Visually Impaired.* Springfield, IL: Charles C. Thomas Publishing, 1997.

Scott, Eileen, Jane Jan, and Roger Freeman. *Can't Your Child See?* Austin, TX: Pro-Ed (2nd ed.), 1985. Designed to help parents raise a child who is visually impaired, this book offers practical suggestions to help parent and child through the different stages of growth. A chapter is included on the child who is blind and has multiple disabilities.

Willoughby, Doris M., and Sharon L.M. Duffy. *Handbook for Itinerant and Resource Teachers of Blind and Visually Impaired Students.* Baltimore: National Federation for the Blind, 1989. A truly comprehensive book with clear, jargon-free information on daily living, explaining different degrees of blindness to classmates and families, medical issues, orientation and mobility, and detailed information on adapting every academic subject for students who are blind.

Videos

Helen Keller in Her Story. New York: American Foundation for the Blind Press. An Oscar-winning documentary of Helen Keller and her teacher Annie Sullivan. Includes vintage still photographs as well as early movie and newsreel footage. (45 minutes)

Not Without Sight. New York: American Foundation for the Blind Press. A look at the major types of visual impairment, their causes, and their effects on vision. Includes camera simulations that approximate what people with each impairment actually see. (20 minutes)

Oh I See. New York: American Foundation for the Blind Press. A look at adaptive methods and materials for elementary and secondary school students with severe visual impairments. It also includes simulations of various visual impairments to help viewers understand why a student may have trouble seeing the chalkboard, reading standard size print, or doing other activities without modifications. (7 minutes)

Out of Left Field. New York: American Foundation for the Blind Press. Panel discussions with blind, visually impaired, and sighted children and adults who discuss the advantages of integrated recreation programs. (17 minutes)

What Do You Do When You See a Blind Person? New York: American Foundation for the Blind Press. A humorous look at misconceptions about people who are blind or visually impaired. (14 minutes)

National organizations

State Services for the Blind and Visually Handicapped (in each state)
1511 K St. NW
Washington, DC 20005
Provides rehabilitation services, communication services, Radio Talking Book 24 hours a day, books (Braille and taped), multimedia library on blindness, plus a store. Minnesota metro area: 651-642-0500; toll-free in Minnesota, (800) 652-9000.

American Council of the Blind
1155 15th St. NW, Suite 720
Washington, DC 20005
(202) 467-5081
(800) 424-8666
(202) 467-5085 fax
A large national membership organization for people who are blind and visually impaired, with affiliates in all fifty states. Offers toll-free information and referral on all aspects of blindness, scholarship assistance to blind/visually impaired postsecondary students, public education and awareness training, and legislative advocacy.

American Foundation for the Blind
11 Penn Plaza, Suite 300
NewYork, NY 10001
(212) 502-7600
(800) AFB-LINE (253-4563)
afbinfo@afb.net
www.afb.org
A national nonprofit organization whose mission is to enable people who are blind or visually impaired to achieve equality of access and opportunity that will ensure freedom of choice in their lives. AFB works toward developing, collecting, and disseminating information; identifying, analyzing, and resolving critical issues; educating the public and policymakers about the needs and capabilities of people who are blind or visually impaired; and producing Talking Books and other audio materials. Offers free newsletters and information.

American Printing House for the Blind
1839 Frankfort Ave.
Louisville, KY 40206
(502) 895-2405
(502) 895-1509 fax
(800) 223-1839
www.aph.org
The world's largest and oldest publishing house for people who are blind. Has a database of books available in Braille or other special media available online. Write for a free sample copy of the "Weekly Reader" in Braille.

Association for Education and Rehabilitation of the Blind and Visually Impaired
4600 Duke St., Suite 430
P.O. Box 22397
Alexandria, VA 22304
(703) 823-9690
(703) 823-9695 fax
www.aerbvi.org
Membership organization that supports professionals who work in all phases of education and rehabilitation of blind and visually impaired children and adults.

Helen Keller National Center for Deaf-Blind Youths & Adults (HKNC)
111 Middle Neck Rd.
Sands Point, NY 11050
(516) 944-8900,
(516) 944-8637 TTY
(516) 944-7302 fax
www.helenkeller.org/national

National Association for the Visually Handicapped
22 W. 21st St.
NewYork, NY 10010
(212) 889-3141
(212) 727-2931 fax
staff@navh.org
www.navh.org
Works with people who are dealing with the difficulties of vision impairment, as well as their families, friends, teachers, and professionals. Produces large-print books.

National Federation of the Blind
1800 Johnson St.
Baltimore, MD 21230
(410) 659-9314
www.nfb.org
This consumer and advocacy membership organization for people who are blind has affiliates in all fifty states, plus Washington, D.C., and Puerto Rico. Provides public information and education about blindness and offers a wide array of aids and appliances.

National Braille Press, Inc.
88 St. Stephen St.
Boston, MA 02115
(888) 965-8965
www.nbp.org
A nonprofit Braille printing and publishing house established in 1927.

Prevent Blindness America
1-800-331-2020
info@preventblindness.org
www.preventblindness.org
A volunteer eye health and safety organization dedicated to fighting blindness and saving sight through public and professional education, community and patient services programs and research. Publishes a kid-friendly poster "10 Myths about Eyesight."

Deaf/Hard of Hearing

Hearing loss covers a wide range, whether temporary or permanent, slight or profound. The vast majority of people with hearing loss have some usable hearing. More people with hearing loss are *hard of hearing* (they can receive some information by hearing alone) rather than *deaf* (hearing loss is so severe that they cannot understand speech through hearing alone and rely on visual methods such as speechreading or sign language). The term *hearing impaired* is sometimes used to refer to all people with hearing loss.

IDEA defines *deafness* as "a hearing impairment that is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification, that adversely affects a child's educational performance." The law, which uses the term *hearing impairment* rather than *hard of hearing*, defines a hearing impairment as "an impairment in hearing, whether permanent or fluctuating, that adversely affects a child's educational performance but that is not included under the definition of deafness in this section."

It can be difficult to talk about people with hearing loss as a group, because individuals are very diverse. People with similar kinds of hearing loss might differ enormously in intelligence, personality, interests, and even their ability to speak and listen.

Hearing loss is often called an "invisible" disability. Even when someone's hearing aids are visible, his or her behavior may seem just like anyone else's. The person may smile and nod appropriately and give the impression that everything is understood. Yet the effects of hearing loss, intellectually and socially, can be enormous. About fifteen or twenty million people in the United States have some degree of hearing loss.

Degree of hearing loss

People frequently use terms such as *deaf*, *hard of hearing*, and *hearing impaired* imprecisely, and the lines between them become blurred. New hearing aids enable many people who would formerly have been deaf to become functionally hard of hearing. Even more important, the terms may obscure the fact that people with hearing losses can hear far better in some situations than others. Many people who can understand speech in small, quiet rooms with one or two people may be effectively deaf in noisy, group situations.

Inappropriate terms used by people not well acquainted with this disability are *deaf and dumb* and *deaf mute*. The use of either term should be discouraged. Instead, just use deaf or hard of hearing.

What causes hearing loss?

Hearing loss has many different causes. Some has hereditary links. Both people who develop hearing loss in later life and children born with hearing loss may have inherited the condition. Hearing loss may be caused by a trauma before or during birth. Until the rubella vaccine was invented, some babies were born deaf because their mothers had German measles while they were pregnant. Deafness in children may also result from illnesses such as meningitis and, less frequently, red measles and scarlet fever. Some life-saving drugs also cause deafness. The cause of hearing loss in many children, however, remains unknown.

Kinds of hearing loss

There are two kinds of hearing loss: *conductive hearing loss* and *nerve (sensorineural) hearing loss.*

Conductive hearing loss

A conductive hearing loss is caused by a problem in the outer or middle ear that reduces the intensity or loudness of sound. Fluid in the middle ear, damage to the eardrum, and hardening of the small bones in the middle ear are frequent causes of conductive hearing loss. Conductive hearing loss often responds to medication or surgery. If it cannot be corrected medically or surgically, a conductive hearing loss can often be overcome successfully with the use of a hearing aid. A conductive loss may interfere greatly with the understanding of speech, but it does not cause profound deafness.

Nerve or sensorineural hearing loss

Nerve or sensorineural hearing loss is the result of damage to the auditory nerve itself, which carries sound impulses to the brain. Nerve hearing loss ranges from a very mild loss to profound deafness.

In the past, nerve hearing loss was not treatable, medically or surgically. Now a surgical implant may provide sound perception for people who are totally deaf. This is called a *cochlear implant*. The cochlear implant is actually a system. Part of it is implanted in the temporal bone (behind the ear), and part is worn externally, like a hearing aid. The implant allows some users to detect and recognize many environmental sounds. It may significantly aid speech understanding with lip-reading and may improve the user's voice modulation.

Nerve hearing loss may cause problems in addition to those caused by conductive loss. Nerve loss may distort sound. A person may hear a sound, but if the sound is amplified it may become unclear or garbled. Also, people with some nerve deafness often hear low-pitched sounds much better than high-pitched sounds. Human speech sounds are in the middle and upper pitches. Moreover, consonant sounds are higher-pitched than vowel sounds, and the consonant sounds are what make English speech comprehensible.

Some nerve losses may be so great that a person is unable to hear anything, even with the strongest amplification available. There are significantly fewer people with this profound nerve deafness than with more moderate nerve losses. Many individuals with nerve hearing losses benefit enormously from hearing aids that help them use their residual hearing to a varying extent.

Are there other complications with hearing loss?

The age at which hearing loss occurs is very significant. If a significant hearing loss occurs before speech and language are acquired, the person is said to be *prelingually deaf*. This dramatically affects the person's whole language development. If someone becomes deaf after acquiring language, particularly in adulthood, the effects on language and knowledge acquisition are much less severe.

One significant difficulty for many people with hearing loss is the lack of background information that people with hearing tend to take for granted. Someone who is deaf or hard of hearing may not pick up information that most hearing people take for granted. People who are hard of hearing have difficulty overhearing conversations or information. They may miss out on radio, TV without captions, and casually imparted information. The language problems of many people with prelingual hearing loss make it difficult to compensate for this lack through reading. What is sometimes mistaken for low intelligence or naivete is, in fact, frequently a result of gaps in information.

How do people with hearing loss communicate?

The core concern with hearing loss is communication. Communication—the exchange of ideas or information—may be verbal (words) or nonverbal (gestures, expressions, images). Spoken language is only one way we can communicate. Writing and signing are other channels. Each language has its own rules for making meanings known.

In the United States, people with hearing loss use a variety of communication methods. Disagreement about which methods are most appropriate or which should be tried first have characterized the history of education and divided many professionals and parents.

Many people with mild hearing loss and those whose hearing deteriorates late in life rely on speech for communication, supplemented by speechreading. Children who are prelingually deaf or who have severe to profound hearing losses, however, learn a variety of communication techniques.

Below are brief descriptions of communication options for people with hearing impairments. Keep in mind that no *one* choice is best for everyone. Visiting with adults who are deaf and hard of hearing can help you develop a realistic perspective of the different methods of communication. Some methods stress hearing and others stress vision. Some are based on spoken language and some in signed language.

Aural-Oral Methods

Aural-Oral methods of communication place importance on speech, use of residual hearing, and speechreading (lip-reading).

The **Auditory-Verbal Method** (or Acoupedic, Unisensory Method) is based on a belief that children who are deaf and hard of hearing can learn to listen and speak by using appropriate amplification and by maximizing use of their residual hearing. This is attempted through intensive one-on-one therapy from an early age, and teaching listening skills with the ultimate goal of including children with hearing loss in regular education programs. This method emphasizes listening and does not allow speechreading during therapy.

The **Auditory-Oral** approach to communication follows a philosophy of establishing verbal communication through meaningful activities designed to promote language learning. This method uses early amplification, speech as primary means of communication, and speechreading.

The **Multisensory Method** is based on a belief that a child who is profoundly deaf can develop spoken language only when additional senses are used to supplement limited hearing. Both vision and touch (tactile clues for development of speech sounds) are utilized.

Manual Methods

Manual communication methods emphasize understanding language using vision and expressing language with the hands. Some forms are accompanied by the spoken word (*simultaneous communication or sim-com*) and some are not.

American Sign Language (ASL) is a unique language. It is a visual-gestural-spatial language in which the placement, movement, and expressing of the hands and body are part of the language. Speech is *not* used while signing ASL because the word order is different.

This language has its own grammar and linguistic principles and can convey abstract thoughts. As with any natural language, ASL is constantly changing. It is the first language of many people who are deaf, especially those with parents who are deaf. English is often taught and learned as a second language. A school program using this approach is called a bilingual/bicultural program.

Pidgin Sign English (PSE) refers to sign language varieties that occur when ASL and English users interact. It involves using ASL signs in a more English word order. The form PSE takes depends on the amount of knowledge the user has of English and ASL. It often occurs naturally for communication between deaf and hearing people. It is not a language itself and is not consistent.

Several invented *sign systems* parallel English. Speech may be used while signing. The theory behind these systems is that if children see all the parts of English, they may then be able to read, write, and possibly speak English.

Cued Speech (sometimes called Cued English) uses hand shapes and hand positions (not signs) near the face. The system shows sounds that are not visible and clarifies sounds that look alike on the lips. There are eight hand cues for consonants and four hand positions and combinations of these positions for vowels. Cued speech can be used for any spoken world language. It shows the exact pronunciation of every syllable of spoken language. The theory is that the system will provide children who are deaf with the same conditions that hearing children have for developing oral comprehension and for language development.

Decisions

Each of these alternatives has strong proponents and opponents. Parents do their own questioning, reading, and talking to people who are deaf or hard of hearing. They think about their own values and their goals for their child before deciding what works for them. There is not a single answer that will fit all situations for all families.

Each family is different, as is each child. The child's input increases and takes over as the child grows up and finds his or her most comfortable means of communication.

Communication and Education

The communication mode of the child and family must be considered throughout a child's school life and educational planning. Any evaluation must use the language the child uses. When determining needs, evaluators must consider the child's method of communication. The needs identified must be addressed in the child's individualized education program (IEP) with goals, objectives and resources to meet those needs. Educational placement, too, will be in part determined by the child's communication method.

IDEA states that the IEP team must "in the case of a child who is deaf or hard of hearing, consider the child's language and communication needs, opportunities for direct communications with peers and professional personnel in the child's language and communication mode, academic level, and full range of needs, including opportunities for direct instruction in the child's language and communication mode.

Social Opportunities

Interaction with other people who are deaf or hard of hearing can help children develop social skills. Meaningful relationships with hearing peers can be hard to maintain and may have little depth. Children need peers and close friends to discuss parents, friends, feelings, and teachers. Through friendships, children find out that their feelings are normal and learn how to cope. Kids who are deaf or hard of hearing want the same information as hearing kids do.

As early as possible, easy communication in a language that is natural to the child can offer basic information. An atmosphere that provides access and interaction with other people who are deaf and hard of hearing, both young and old, with whom the child can share information and problems, can help develop healthy self-respect and social skills.

Socialization/Peer Interaction Resource Ideas

The following are some ideas of places children can meet other children and adults who are deaf or hard of hearing:

- **Camps and conventions**—Organizations that serve people who are deaf and hard of hearing compile annual lists of camps for children, conferences and opportunities for families, etc.
- **Churches**—Deaf churches and houses of worship regularly employing an interpreter are good places to meet children and adults who are deaf and hard of hearing.
- **Parent and family networking**—Service organizations will "match" families living close to each other by request.
- **Regional Service Centers for Deaf and Hard of Hearing Persons** (RSCs)—RSCs are located throughout the state and can help in locating deaf or hard of hearing adults who may be interested in interacting with deaf or hard of hearing children.
- **Deaf clubs**—Locate them through RSCs.
- **Daycare**—Some families have searched for a daycare provider who is deaf so their children can interact regularly with a deaf adult.
- **"Socialization Day"**—Many communities hold an annual event where all children with hearing loss, their families, and professionals who work with them get together for day-long learning and social activities.
- **"Interaction Plan"**—Developed in Oklahoma, any program with fewer than fifteen students who are deaf or hard of hearing plans ways in which their students will have opportunities to interact with their peers from other programs in the state, as well as with the deaf and hard of hearing communities; in addition, mainstream and residential programs are expected to participate in each other's activities.

This information was provided by Carolyn Anderson who is a parent and PACER Parent Advocate. Some information was adapted from Knowing The R.O.P.E.S by Carolyn Anderson (Minneapolis: Doorways, 1994).

Tips for talking with people who are deaf or hard of hearing

Facial expressions, gestures, and lip and body movements are all visual cues that people with hearing loss use. Visual cues, together with the auditory signal, further improve understanding. Make every effort to enhance the visual cues available to the person with hearing loss. For example:

1. Avoid chewing, eating, smoking, or covering your mouth with your hands.
2. Do not exaggerate sounds or elaborately mouth words when speaking. This distorts the message and makes facial cues difficult to interpret.
3. Make sure your face and body can be easily seen by the person with hearing loss.
4. Good lighting is essential. For example, light should shine on the speaker's face rather than in the eyes of the person with hearing loss.
5. When you speak, face the person with hearing loss directly and at the same level.
6. The greater the distance between a person with hearing loss and the speaker, the softer the sound and the more difficult it is to use visual cues effectively. The optimal distance between speaker and listener is from three to six feet.

Environmental noise can hamper the ability of a person with hearing loss to understand speech. Try to arrange the environment so the person with hearing loss is away from any noise source.

1. Avoid speaking too rapidly. Speak slowly and pause between sentences and phrases. Wait to make sure you have been understood.
2. Never speak directly into a person's ear. This may further distort your message and hide all visual cues. Sentences spoken a bit more slowly are much clearer than those that are shouted.
3. If the person with hearing loss does not appear to understand what you've said, rephrase the statement with different words using short and simple sentences.
4. Sudden changes in topic can be extremely confusing to an individual with a hearing loss. Whenever possible, provide clues to the new topic of conversation.
5. Recognize that everyone, especially the person with hearing loss, does not hear as well when he or she is tired or ill.

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This material was originally reviewed and updated by Linda Berman, a member of PACER's Board of Directors and a parent of a child who has hearing loss, and Harvey Hoffman, Courage Center, coordinator of programs for people with hearing loss. Updated by PACER Parent Advocate, Carolyn Anderson, 2000.

What is deaf-blindness?

Occasionally, children may have both hearing loss and a vision loss. When this requires a special type of educational program, IDEA regards it as a separate educational category.

The law defines deaf-blindness as "concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness."

Children who are deaf-blind are often taught to communicate by using the manual alphabet spelled directly into the palm of the hand and through American Sign Language.

Measurement and remediation of hearing loss

Hearing loss can be measured by sophisticated equipment administered by a trained audiologist. The hearing loss of newborn babies and very young children can be determined with a fair degree of accuracy.

Hearing loss is expressed in terms of decibels (dB)—the intensity of a pure tone of sound. A loss of 25 dB is mild; a loss of 75 dB is considered severe. (A noise level of about 85 dB is the threshold for noise pollution.) Hearing can be measured up to about 110 dB. Hearing tests also examine which frequencies (Hz) or pitches of sound can be heard and at what intensity. This is important because of the pitches of human speech.

The science of audiology, the measurement of hearing, and the development of modern hearing aids date from efforts to rehabilitate veterans with hearing loss following World War II. Systematic, early fitting of young children with appropriate hearing aids dates only from the 1950s. Today, infants as young as a few days old may be fitted with hearing aids. Recent miniaturization has permitted many people with severe or profound losses to wear behind-the-ear hearing aids. Twenty years ago, these children would have had to wear very bulky hearing aids that were less effective.

Hearing aids now permit many hard of hearing people to approach normal hearing in many situations. They enable other people, who would otherwise be deaf, to become functionally hard of hearing in some situations. Combined with speechreading and/or sign language, hearing aids are invaluable for many children with hearing loss.

Hearing aids do have limitations, however. They do not do for poor hearing what eyeglasses often do for poor eyesight.

1. Hearing aids are only aids. They are unable to make a person hear perfectly.
2. Hearing aids are delicate and can malfunction.
3. They depend on batteries; toward the end of a battery's life, hearing aids become less powerful.
4. The earmold, which is custom-fitted into a person's ear, must be fitted exactly. Growing children need to have new earmolds made frequently.

There are other even more serious limitations. Hearing aids amplify the noises in the environment, as well as speech. This makes it very difficult to discriminate speech sounds. In some cases, environmental sounds can be unpleasantly loud. A person who is hard of hearing may be delighted to hear a pin drop, but a fork dropping may sound like a loud crash. A person with a hearing aid may hear clearly in a quiet room with one or two people but be unable to hear in a loud room with many people talking at once, like in a school lunchroom. Some hearing aids can be programmed to amplify sounds more discriminately.

Secondly, hearing aids become less effective with distance. If a speaker is more than three or four feet from the hearing aid microphone, the aid begins to lose effectiveness. The FM auditory trainer (used in many schools and often referred to by its trade names as Phonic Ear, Telex, Oticon, or personal FM system) overcomes this problem to some degree: the speaker's voice comes in on FM radiowaves more clearly than environmental noises and always operates at the most desirable distance from the wearer's hearing aid. The teacher or speaker wears what looks like a microphone but is actually a FM radio transmitter; the student receives the signal on a receiver.

Assistive technology for hearing loss

People with hearing loss use many types of assistive technology devices:

Auditory trainer. This device has a receiver and a microphone. The child wears a receiver, while the teacher or parent wears a microphone. The auditory trainer amplifies the voice of the speaker, but not the background noise.

Communication devices. Many people with hearing loss increasingly take advantage of other electronic devices that help to bridge the communication gap. Special telephones for people with hearing loss, *TDDs* (telephone devices for the deaf) or *TTYs* (teletypewriters) enable people to use telephones to communicate written messages to others with similar devices. *Relay services* enable people with hearing loss to make calls to people with regular telephones (doctors, employers, etc.). The relay operator acts as an intermediary between the caller using a TDD and the person who can hear who does not have a TDD. *E-mail* may replace TDDs for many. *TV adapters* decode closed captions on many TV programs, as well as real-time captioning for classrooms and other audience forums.

Hearing aids. These instruments increase the volume of all sound. They may be worn on the body, behind the ear, or sometimes attached to glasses. Aids may be used for one ear or both.

The purpose of a hearing aid is to amplify and reproduce sound to enhance hearing. Amplified sound is louder than unaided sound; a sound occurring ten feet away may seem like it is four feet away when heard through a hearing aid.

Hearing aids are usually worn behind the ear (BTE), in the ear (ITE), or on a pair of eyeglasses. A person may wear one aid or two aids. Most children wear BTE aids as opposed to ITE or eyeglass hearing aids.

An audiologist determines the type of aid a child wears. Audiologists are qualified to evaluate hearing loss and make recommendations for habilitating the hearing loss, which may include hearing aids.

Federal and state laws govern the sale of hearing aids and stipulate that a person with a hearing loss must have a medical evaluation by a licensed physician before purchasing an aid. Children with a hearing loss should be directed to an audiologist because hearing aids require a doctor's prescription. Dealers may not sell hearing aids without a prescription. Under Minnesota law, a waiver to this ruling can be signed by people over 18 and under 60, if the dealer reads the specific requirements in the Federal Register of February 15, 1977, to that person. No child should ever be wearing a hearing aid that has not been specifically recommended by an audiologist and a physician.

Who maintains the hearing aid?

Most children with hearing loss use some form of amplification. It is essential that the hearing aid work optimally during school hours. Younger children will not always be able to monitor and check the functioning of their aid.

IDEA states that the school district shall insure that hearing aids worn in school are functioning properly. A hearing aid is not a complicated instrument. Learning how to care for a hearing aid does not require one to know how it works mechanically. In addition, hearing aid maintenance should not solely be the responsibility of the classroom teacher. Classroom teachers should know the following:

1. *Who is the resource person in the district responsible for maintaining records and any additional equipment for the child with a hearing loss?*
2. *The different types of hearing aids commonly worn by children.*
3. *The parts of a hearing aid*
4. *How to check a hearing aid by listening to the instrument and by observing the auditory behavior of the child.*

It is possible that in some schools there will be no one on staff who knows about hearing aids other than the classroom teacher. But someone in the district should be familiar with the maintenance necessary to keep the aids functioning properly. Any team member who has direct contact with the child shares the responsibility of maintaining the hearing aid.

Hearing Aid Dos and Don'ts

1. *Keep the hearing aid dry.*
2. *Always turn the aid off when it is not being worn.*
3. *Do not take the aid apart and attempt to repair it.*
4. *Do not place the aid in extremely hot or cold places (for example, do not place an unworn aid on a heater).*

Listening checks for a hearing aid

Teachers should do a listening check of a hearing aid whenever they suspect that a hearing aid isn't working properly. This implies that the teacher can "see" that the child cannot hear. Here are a few things teachers should know about each child with hearing loss in their classrooms:

1. *Does the child know how to put on his or her aid?*
2. *Does the child know when the aid is off or on?*
3. *Does the child follow directions without looking at you?*
4. *Does the child know how to change the battery in her or his aid?*
5. *Does the school have spare batteries for the child's aid?*

If the answers to the above questions are yes, then it will be easier to spot an aid that is not functioning properly. In these cases the child will likely tell you that his or her aid is not working. It is important that the teacher know what is normal listening behavior for the child. If the child seems unusually inattentive or unusually moody, a listening check is advisable.

Care of the earmold

Some children who wear hearing aids maintain the earmold by washing it appropriately at home. The classroom teacher can check for wax accumulation in the earmold canal tip. A plugged opening will reduce the amplification of the aid significantly, and the child may act as though he or she does not hear. A plugged earmold may also produce a squealing feedback sound. If the opening is plugged, simply remove the wax with a toothpick, pin, or pipe cleaner. If the earmold appears to be grossly impacted with wax, remove the earmold piece from the hearing aid and wash in mild soap and water. Blow out the water before placing the mold back on the hearing aid. Do not use alcohol for cleaning; over time, alcohol hardens the mold and leaves it uncomfortable to wear.

Questions children ask about deafness

Jay wears a body aid and has a receiver "button" in his ear. Although he is profoundly deaf, he communicates with speech and sign language and can speech-read. His speech is somewhat difficult to understand.

Q. Do you always wear your hearing aid?

A. Oh yes, whenever I'm awake. But, I don't wear it when I swim, take a bath, or sleep. Sometimes when I'm in a room that's very noisy, I turn it off because the sounds get so loud and garbled.

Q. Can you play outside even though you can't hear what's going on?

A. Sure, I just have to WATCH out for things—like Frisbees, baseballs, and cars. Some things I can feel—like thunder, or a heavy truck rumbling down the road. I'm very careful when I cross the street—I look very carefully both ways.

Q. Can you hear sounds in your house?

A. Some sounds, even some speech, I can hear, but I have to listen very hard. Some sounds I can feel—like the stereo. If it's very loud, I can also hear it—or the radio—even the vacuum cleaner, if Mom wants my attention, she stamps twice on our wooden floors, and I turn around. But I can't hear the doorbell or telephone. We have the doorbell wired to make a light flash on and off so you know someone is at the door.

Q. Can you use a telephone?

A. If the light for our phone flashes, I just pick up the phone and say, "Hello, wait a minute please." Then I go get someone, usually one of my sisters (the phone is usually for one of them anyway), and then they pick up the phone and find out who it's really for. So no, I can't hear on a regular phone, but . . .

Mom and Dad set up an email account for me on our home computer. I can type and email to all my friends who have email too.

Q. How did you learn sign language?

A. Just like you learned speech. My family and teachers (I started having teachers come to my house when I was just a year old) would name everything I saw or wanted and use signs all the time, and I learned to sign.

Q. How could you learn speech if you can't hear your voice?

A. My family always talks to me, too, and sometimes I catch a bit of sound from my Dad's deep voice. But it's really hard. My speech teacher and I have worked a long time and I would sit in front of a mirror to see the shape of my mouth. I also would feel my throat and nose to feel vibrations.

Q. On TV, what does "closed captioned for the hearing impaired" mean?

A. Captions are printed words at the bottom of a TV screen to give information or to explain what is going on. You've probably seen captions for weather bulletins at some time. Well, closed captions show only on TV screens of people who buy decoders for their TV. People who are hearing impaired like TV decoders, so they can fully understand the programs through the captions.

Q. Do your ears hurt?

A. No. Being deaf isn't painful. It's just that my ears don't get the sound waves to my brain like yours do.

Simulation activities for hearing loss

SILENT MOVIE

Age level: preschool and elementary
Equipment: a cartoon or short video unfamiliar to class.
How to play: *For elementary students:* Run the video in its entirety without sound. Let the class discuss what they thought went on, or have them write their ideas about what happened or what was said in the video. Then rerun the video with sound and have children compare their notes with what actually happened. Discuss their feelings about not being able to hear.

For preschoolers: If the class has a TV, turn sound off for one minute of Sesame Street and see if the students can tell what is going on.

SILENT TIME *or* SILENT MEAL

Age level: elementary school
Equipment: none
How to play: Designate a portion of the day (such as one hour) when no one can talk. To get something, they have to gesture. To understand, they have to read lips or gestures. To express a thought, they may have to act out or dramatize. (Do not allow students to communicate by writing notes—that's too easy.) Discuss which things were easy to communicate and which were difficult.

CATCH THE WORDS

Age level: elementary school
Equipment: chalk and eraser for leader or teacher, paper and pencils for the children.
How to play: The leaders, without talking, should write a word or sentence on the board, erasing each letter as soon as it is written. The students must write the same word or sentence on their papers. Have them discuss how complete the word or sentence is on their papers and the difficulties they may have felt in trying to catch by sight everything that was printed. Repeat the activity, this time with the leader saying aloud each letter or word as it is printed. Does "hearing" make the activity easier?

PANTOMIME

Age level: all ages
Equipment: none
How to play: Discuss how signs are used in many instances to give information: traffic officers, umpires, construction workers. Have each child convey some action or information without using words: brushing teeth, putting on a coat, pouring a glass of milk, etc. Act out a familiar story.

SOUNDTRACK

Age level: all ages
Equipment: tape recorder and cassette tape
How to play: Record a conversation with a friend in a noisy place (e.g., outside to pick up traffic noises or at a party with music and many people talking). Have someone listen to the conversation and tell you what is being said. Hearing aids, like the tape, amplify all sounds. See how hard it is to separate all the sounds. This give kids a glimpse into how frustrating it can be to be hearing impaired.

Resources

Books for children

Addabbo, Carole. *Dina the Deaf Dinosaur.* Stamford, CT: Hannacroix Creek Books, 1998. This children's book will delight children who can hear or who are deaf. Sign language is taught in a creative and memorable way. (P)

Ancona, George, and Mary Beth Miller. *Handtalk Zoo.* New York: Aladdin, 1996. Photograph book of a visit to the zoo with actress Mary Beth and children learning to sign names for the animals they encounter. (P)

Aseltine, Lorraine, and Evelyn Mueller. *I'm Deaf and It's Okay.* Morton Grove, IL: Albert Whitman, 1986. When a young boy who is deaf realizes that he will always have to wear hearing aids, he rebels. He is inspired by an older boy who visits his class. The authors are teachers of the deaf and a mother of a child who is deaf. (P, M)

Blatchford, Claire. *Nick's Mission.* Minneapolis: Lerner Publications, 1995. Nick, a sixth grader who is deaf, is upset about having to go to speech therapy over the summer, until he and his dog stumble on some dangerous smugglers and learns the importance of being able to communicate. (P, M)

Booth, Barbara. *Mandy.* New York: Lothrop, Lee & Shepard, 1991. A beautiful story about a young girl who is deaf and her relationship with her grandmother. Mandy hates the dark because she cannot see signs, but overcomes her fears. Strikingly illustrated. (P, M)

Herigstad, Joni. *I Was So Mad!* Los Alamedos, CA: Modern Signs Press, 1982. A playground tiff escalates into feud proportions, then is happily resolved by matching apologies. The whole tale is told in simple English, signs, and lively illustrations. (M)

Hill, Eric. *Where's Spot?* (sign language edition) New York: Putnam, 1987. Each colorful page of this childhood favorite features an illustrated sign language translation. Children will enjoy the classic story as they learn the signs that correspond to the printed words.

Hodge, Lois L. *A Season of Change.* Washington, DC: Gallaudet University Press, 1987. Biney is usually a cheerful teenager, but she is tired of having people treat her as a problem, just because she doesn't hear very well. She finally gets a chance to show everyone how capable she really is. (M, U)

Lakin, Pat. *Daddy and Me in the Morning.* Morton Grove, IL. Albert Whitman, 1994. A deaf boy and his father share a special time as they watch the sun rise at the beach. (P)

Lee, Jeanne M. *Silent Lotus.* New York. Farrar, Straus and Giroux, 1991. Although she cannot speak or hear, Lotus trains as a Khmer court dancer and becomes eloquent in dancing out the legends of the gods. (P)

Levi, Dorothy Hoffman and Ethel Gold. *A Very Special Sister.* Washington, DC: Gallaudet University Press, 1992. Laura's mother becomes pregnant and she worries that if the new baby is able to hear, will she be loved more by her parents? (P)

Litchfield, Ada. *A Button in Her Ear.* Morton Grove, IL: Albert Whitman, 1976. A little girl tells how her hearing problem is detected and corrected with the use of a hearing aid. (P, M)

MacKinnon, Christy. *Silent Observer.* Washington, DC: Kendall Green, 1993. A picture book autobiography of a little girl in the late 1800's who lost her hearing to illness and went away to a school for the deaf. (P, M)

Mango, Karin N. *Hearing Loss.* New York: Franklin Watts, 1991. Describes the conditions and varying degrees of hearing loss and deafness, and discusses methods by which the hearing-impaired can communicate with others. (M, U)

Peterson, Jeanne Whitehouse. *I Have a Sister, My Sister is Deaf.* New York: Harper, 1977. A warm, mutually supportive relationship between two sisters makes this a sensitive book depicting an exceptional child in the family. (P, M)

Rankin, Laura. *The Handmade Alphabet.* New York: Dial, 1991. A striking interpretation of the manual alphabet used by the deaf to communicate visually. The accuracy and grace of the illustrations are exceptional. For all ages.

Scott, Virginia M. *Belonging.* Washington, DC: Gallaudet University Press, 1986. Fifteen-year-old Gustie loses her hearing after an illness. She must now learn how to accept her hearing loss and understand the changes it brings. (U)

Shreve, Susan Richards. *The Gift of the Girl Who Couldn't Hear.* New York: Beech Tree, 1991. Two friends, one of who is deaf, help each other with tryouts for a seventh-grade production of "Annie." (P, M)

Starowitz, Annie Marie. *The Day We Met Cindy.* Washington, DC: Gallaudet University Press, 1985. In this delightful picture storybook, a first grade class meets Cindy, who is the aunt of one of the students. Cindy has a hearing loss. The story explains how the students decide to learn sign language so they could communicate with Cindy. (P, M)

Sullivan, Mary Beth; Burke, Linda. *A Show of Hands: Say It in Sign Language.* New York: Harper, 1991. Large cartoon-like drawings illustrate sign language and finger spelling. (P)

Wheeler, Cindy. *Simple Signs.* New York: Viking, 1995. Demonstrates through illustrations and brief text twenty-nine American Sign Language signs for words such as *hello, cry, dog* and *love.* (P)

Wheeler, Cindy. *More Simple Signs.* New York: Viking, 1998. More words that kids actually use in their daily lives. (P)

Wolf, Bernard. *Anna's Silent World.* New York: Harper, 1991. Anna was born with a profound hearing loss, but leads an active life. (M, U)

Books for adults

Candish, Patricia Ann Morgan M.L.S. *Not Deaf Enough: Raising a Child Who is Hard of Hearing.* Washington, DC: Alexander Graham Bell Association for the Deaf, 1996. A primer for parents on raising a child with hearing loss and advocating for your child at school.

Cleve, Jon Van, ed. *Gallaudet Encyclopedia of Deaf People and Deafness.* Riverside, NJ: McGraw Hill, 1987. See if a local library has this comprehensive reference written by 300 experts on deafness and hearing impairment from around the world in the fields of sociology, audiology, law, education, psychology, history, and rehabilitation.

Freeman, Roger D.; Clifton F. Carbin, and Robert J. Boese. *Can't Your Child Hear? A Guide for Those Who Care About Deaf Children.* Austin, TX: Pro-Ed, 1981. A comprehensive guide for parents of children who have severe to profound hearing loss that occurred before the development of speech. The authors, two physicians and a psychologist from the University of British Columbia, favor a total communication approach.

Golan, Lew. *Reading Between the Lips: A Totally Deaf Man Makes It in the Mainstream.* Chicago: Bonus Books, 1995. Golan was already reading and writing and talking when he was deafened by spinal meningitis at age five. In this memoir, the author writes about survival in the mainstream without sign language.

Kisor, Henry. *What's That Pig Outdoors: A Memoir of Deafness.* New York; Penguin, 1991. A memoir written by a Pulitzer Prize–winning journalist who lost his hearing at age three. He recounts the compelling story of his life from the perspective of a deaf person in a hearing culture.

Lane, Harlan. *When the Mind Hears: A History of the Deaf.* New York: Vintage Books, 1989. An important history of deaf education written by the outspoken proponent of American Sign Language

Lane, Harlan, and Bonnie Meath-Lang. *Deaf Persons in the Arts and Sciences,* 1996. San Francisco: Greenwood Press. This collection of 150 biographical sketches of outstanding achievers who were deaf focuses on how their deafness affected their work and perspective.

Marschark, M. *Raising and Educating a Deaf Child.* Oxford: Oxford University Press, 1997. Drawing from current educational and scientific journals and research, the author pulls together a practical and readable guide on the language, social, and intellectual development of deaf children, focusing on everyday issues as well as learning and education.

Medwid, Daria J., and Denise Chapman Weston. *Kid Friendly Parenting With Deaf and Hard of Hearing Children: A Treasury of Fun Activities Toward Better Behavior.* Washington, DC: Clerc, 1995.

Neisser, Arden. *The Other Side of Silence: Sign Language and the Deaf Community in America.* Washington, DC: Gallaudet University Press, 1990. Explores the deaf community through interviews from across the country. This seminal book reveals the warmth, creativity, and resilience of deaf people, and offers an update of the community today.

Oberkotter, Mildred. *The Possible Dream.* Washington, DC: Alexander Graham Bell, 1990. Ideas from parents of children who have hearing loss, and the students who as a group favor the use of oral/auditory methods and mainstream settings.

Pollack, Doreen. *Educational Audiology for the Limited Hearing Infant and Preschooler.* Springfield, IL: Charles C. Thomas, 1985, 2nd ed. Very complete explanation and argument for "acoupedic" method to maximize residual hearing in infants and small children. Includes diaries of mothers of children with hearing loss recording their frustrations and successes.

Sacks, Oliver. *Seeing Voices.* Berkeley: University of California Press, 1989. A leading neurologist and popular author writes about deafness, the culture of the hearing-impaired, and the modes of communication.

Schlesinger, Hilde S., and Kathryn P. Meadow *Sound and Sign, Childhood Deafness and Mental Health.* Berkeley: University of California, 1982. Excellent study of the implications of deafness on children's social and emotional development by a psychiatrist who has worked extensively with deaf children and teachers of the deaf.

Schwartz, Sue. *Choices in Deafness: A Parent's Guide to Communication Options.* Bethesda, MD: Woodbine House, 1996. An invaluable guide to the world of deaf education. The author takes an unbiased look at several communication options: Auditory-Verbal, Bilingual-Bicultural, Cued Speech, Oral, and Total Communication. Each option contains an outline of the option, and stories of three or four children who are using this option. The stories written by the children's parents provide insight into how they chose the option that was right for their child.

Miller, Joan Heller. *The New Language of Toys: Teaching Communication Skills to Special Needs Children.* Bethesda, MD: Woodbine House, 1996.

Magazine for adults

Shhh
7800 Wisconsin Ave.
Bethesda, MD 20814
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(301) 657-2249 (TDD)
Published bimonthly by Self-Help for Hard of Hearing People, Inc.

Videos

Sign of the Times. Boston: Fanlight, 1997. The stories of high school basketball player Diondre, who is deaf, and Vicki, the sign-language interpreter who makes it possible for him to be a star. (23 minutes)

Voices in a Deaf Theater. Boston: Fanlight, 1996. (24 minutes)

National organizations

Alexander Graham Bell Association for the Deaf and Hard of Hearing
3417 Volta Pl. NW
Washington, DC 20007
(202) 337-5220 voice/TTY
(202) 337-8270 fax
www.agbell.org
This membership organization disseminates information, offers financial aid and scholarships to individuals with hearing loss, and provides support and networking through local affiliates. Its publication catalog offers an extensive listing of texts, brochures, audiovisual materials, and software available for auditory-oral education.

American Society for Deaf Children
1820 Tribute Rd., Suite A
Sacramento, CA 95815
(800) 942-ASDC (voice, TTY)
An organization of parents and families that advocates for deaf or hard of hearing children's total quality participation in education, the family and the community.

American Speech-Language-Hearing Association (ASHA)
1080 1 Rockville Pike
Rockville, MD 20852

Better Hearing Institute
Hearing Helpline
P.O. Box 1840
Washington, DC 20013
(800) 424-8576
(800) EAR WELL
www.betterhearing.org
Information on hearing loss, tinnitus, and hearing aids, as well as a directory of hearing care providers.

Gallaudet University
800 Florida Ave. NE
Washington, DC 20002
(201) 652-5000 (voice or TDD)
(800) 672-6720, ext. 5176 (voice or TDD)
www.gallaudet.edu
Gallaudet University Press, associated with the university, has an extensive publishing program on deaf and hard of hearing issues. Call for a catalog, or check it out online at *http://gupress.gallaudet.edu*

National Association of the Deaf (NAD)
814 Thayer Ave.
Silver Spring, MD 20910
(301) 587-1788 voice
(301) 587-1789 TDD
(301) 587-1791 fax
www.nad.org
This consumer organization focuses on grassroots advocacy and empowerment, captioned media, information dissemination, legal assistance, and youth leadership.

National Information Center on Deafness (NICD)
Gallaudet University
800 Florida Ave. NE
Washington, DC 20002
(202)651-5051 voice
(202)651-5052 TTY
(202)651-5054 fax
nicd@gallux.gallaudet.edu
www.gallaudet.edu/~nicd
A centralized source of accurate, up-to-date, objective information on topics dealing with deafness and hearing loss. NICD responds to a wide range of questions received from the general public, deaf and hard of hearing people, their families, and professionals who work with them.

Physical Disabilities

Physical disabilities are included under IDEA in the category *orthopedic impairment.* The term is defined as "a severe orthopedic impairment that adversely affects a child's educational performance." The category includes impairments caused by congenital anomaly (clubfoot, absence of a member, etc.), impairments caused by disease (poliomyelitis, bone tuberculosis, etc.), and impairments from other causes (cerebral palsy, amputations, spinal cord injuries, and fractures or burns that cause contractures).

Many children who have orthopedic impairments have average or above average intelligence and learn well in a regular classroom. Most of these children need adaptive aids for learning or the help of a teacher's aide.

This chapter discusses eight of the most common physical impairments: cerebral palsy, spina bifida, spinal cord injury, muscular dystrophy, juvenile rheumatoid arthritis, multiple sclerosis, brittle bone disease, and amputation.

Cerebral Palsy

Cerebral palsy is a permanent disability caused by damage to the motor cortex of the brain. *Cerebral* refers to the brain and *palsy* refers to lack of control over the muscles. Injury to the brain that results in cerebral palsy usually occurs before, during, or shortly following birth. Any damage to the brain—whether caused by delayed development, injury, or disease—may produce cerebral palsy.

Cerebral palsy includes a large number of neuromuscular disorders of differing severity levels and symptoms. For the disorder to be classified as cerebral palsy, the problem must not only involve muscle movement or posture but also occur early in development at the time of the brain's most rapid growth. In some cases, cerebral palsy may be accompanied by mental or emotional impairment, convulsive seizures (called epilepsy), or losses in hearing, vision, or the other senses. Some of these associated conditions can be treated successfully, and some kinds of cerebral palsy can improve with intervention. However, the nerve cells involved are limited in their powers of repair and regeneration.

What causes cerebral palsy?

The chief cause of cerebral palsy is insufficient oxygen to the brain of a fetus or newborn child. The disability may also be associated with premature birth, blood type compatibility between parents, the mother's infection with German measles or other viral diseases in early pregnancy, and microorganisms that attack the newborn's central nervous system. Most cerebral palsy is congenital. A less common type, acquired cerebral palsy, can be caused by injury, such as motor vehicle accidents, falls, or child abuse.

The disorder occurs in about 2.5 out every 1,000 people. An estimated 500,000 people in the United States have cerebral palsy; each year approximately 5,000 cases are diagnosed in infants and babies and 1,200 to 1,500 preschoolers.

Types of cerebral palsy

There are three main types of cerebral palsy. A person with cerebral palsy may have just one type or a combination of one or more types.

Spastic cerebal palsy is the most common type. It involves stiff and difficult movement. When reflexes are tested, responses may be very brisk, resulting in repeated contractions. If a child with spasticity is supported under the arms, the legs often lay straight down, unable to flex at the knees. The lower legs turn in and cross at the ankle. The movements of the legs are stiff and resemble the cross blade of a pair of scissors, hence the term "scissors gait." This condition can sometimes be corrected by surgery.

Athetoid cerebral palsy is characterized by involuntary movements of affected parts of the body. This incessant, slow activity is called *athetosis*. The hands may turn in and twist and there may be facial grimaces, poor tongue control, and drooling. Another form of involuntary movements occurring with athetosis involves abrupt flailing or jerky motions of the body.

Ataxic cerebral palsy involves lack of balance and coordination. Persons with ataxia may sway when standing, have trouble maintaining balance, and often walk with feet spread wide apart to avoid falling.

Is cerebral palsy a hereditary disease?

No. Cerebral palsy is a condition, not a disease, and is not hereditary. It is neither progressive nor communicable. It is not "curable," although training and therapy can improve the quality of life for many people with cerebral palsy.

Can cerebral palsy be treated?

Professionals talk about *managing* cerebral palsy rather than *treating* it. Management involves using a variety of methods and devices to help children achieve their maximum potential in growth and development. Management should begin as early as possible after children are identified. Careful attention to the child's movement, learning, speech, hearing, social, and emotional development by a team of professionals that includes physicians, therapists, educators, nurses, social workers, and others can help the family as well as the child. Medications, surgery, and braces are sometimes used to improve nerve and muscle coordination or to prevent and correct deformity.

As children grow up, they may require support services such as a personal care attendant, continuing therapy, special education, vocational training, living accommodations, counseling, transportation, and employment opportunities—all essential to the developing adult. People with cerebral palsy need, most of all, the opportunity to live as normally as possible in our society. Depending on the degree of motor impairment, most people with cerebral palsy can be very self-sufficient with appropriate adaptive aids and appliances and support services.

Feelings about having cerebral palsy

Dear Teachers,

My name is Chris Johnson. I am writing this letter to tell you a little bit about me and what kinds of things help me get the most out of school. I am 13 years old. After I was born, the doctors told my parents that I had Cerebral Palsy (CP).

Some of my interests include writing stories, basketball, baseball, drawing, any type of artistic project, listening to music (classical, rock & roll, a little bit of heavy metal, country, blues and jazz), hanging out with friends, socializing, going to the movies, and cruising around with my family.

Having CP basically means that some of your muscles are weak or you can get startled easily and jump. Also, you may not be able to do some tasks as fast as other classmates.

Having CP doesn't mean that you are not intelligent and cannot be as good or better than other students on assignments.

On a day-to-day basis, CP affects my life in this way:

— I am not able to participate in certain sports or in certain exercises in gym.

— Both of my hips are dislocated and that can cause extreme piercing pain in both of my legs and hips.

— I take arthritis medicine daily for the pain. There may be some side effects. For example, I may have stomach discomfort.

— Some kids may be upset or angry because some of my assignments may be changed to fit my needs.

— I need help with things like getting books from my book bag, getting in and out of bed, going to the toilet, getting into a vehicle, getting dressed, etc.

Things that help me get the most out of school are things like:

— Having alternatives to longer written work, such as additional time to write things out, access to a computer, dictating assignments when necessary, brief rest periods for longer testing,.(Short answer work can be done without adjustments.)

— Taking breaks and being repositioned due to physical discomfort.

— When switching chairs, I need two people to help run the hoyer lift, which is designed to make lifting easier.

— Extra set of books to keep for use at home.

— Adapt a locker: lower the shelf and hook, and make it so I can open it myself.

— Help in the lunch line.

— Pupil Support Assistant to help with using the restroom.

— Having classmates pick up hard to reach things.

— Ramps instead of steps.

— Cooperative learning activities with other kids.

In conclusion, other educational considerations include:

— Cooperative learning ideas.

— Being able to leave classes early in order to get to the next class.

— When leaving for therapy or daily exercise and stretch periods, making sure assignments are recorded and given to me by my teachers.

I'm looking forward to a good year in 7th grade. I hope all things will work out well.

Sincerely,
Christopher L. Johnson

Questions children ask about cerebral palsy

Sally cannot walk because of her CP, so she uses a wheelchair. Because Sally's speech is also difficult to understand, children may have to listen very carefully.

Sally's hands do not work very well. It is easier for her to write with a large pencil or crayon, to brush her teeth with an electric toothbrush, and play card games with a special holder for the cards.

Sometimes Sally does her homework on a cassette tape so the teacher can listen to it. She uses a computer with a key guard that allows her to select one key at a time. Sally can rest her hand onto of the keyboard without touching too many keys at once. This has been an excellent adaptation for doing her homework and producing legible work.

Sally talks about going to camp and horseback riding. She can play soccer, using the wheelchair to kick and block the ball.

Q. Can you walk?

A. No, I can't because of my cerebral palsy. When I was born, the part of my brain that controls my muscles was injured. So it's hard for me to make my legs do what I want them to do. My muscles tighten up and don't work right. Some people with cerebral palsy can walk. Others need braces on their legs and walk with crutches or a walker. I use my wheelchair to get me where I need to go.

Q. How do you eat?

A. I have a special spoon with a big handle that is easier for me to hold. I use a straw in my cup for drinking because that works better for me. My plate has a lipped edge so the food goes onto my spoon and not the table.

Q. How do you get dressed?

A. My mom helps me, but I do as much as I can by myself. I pick out what I want to wear. I wear clothes like sweatshirts that don't have buttons and zippers, because they're hard for me to do. I also like Velcro straps on my shoes, because I can "tie" them easily. Some of my friends who have cerebral palsy tie their shoes just loose enough to slip into them.

Q. How do you hold your head still for a dentist?

A. Before I go to the dentist, I take a muscle relaxant that the doctor ordered for me. Then my head is very relaxed. I'd feel real bad if I accidentally bit the dentist's fingers.

Resources

Books for children

Adler, Carole S. *Eddie's Blue-Winged Dragon*. New York. Putnam, 1988. A sixth grader with cerebral palsy becomes the owner of a brass dragon who helps him out in some of the battles he faces due to his disability. (P, M)

Aiello, Barbara, and Jeffrey Shulman. *It's Your Turn at Bat*. Lafayette, LA: Twenty-first Century Books, 1988. A fifth grade boy with cerebral palsy discovers that the money he was responsible for is missing. Includes a question and answer section about what it's like to have cerebral palsy. (M, U)

Bergman, Thomas. *Going Places: Children Living with Cerebral Palsy*. Milwaukee: Gareth Stevens, 1991. This is a gentle biography of six year old Mathias, a boy who has cerebral palsy. (P)

Carter, Carol S., and Alden R. Carter. *Stretching Ourselves: Kids with Cerebral Palsy*. Morton Grove, IL: Albert Whitman, 2000.

Emmert, Michelle. *I'm the Big Sister Now*. Morton Grove, IL: Albert Whitman, 1989. Michelle and Amy Emmert are actual sisters. Nine-year-old Michelle talks about living with a sibling who has cerebral palsy and is severely disabled. Even though Amy is five years older, Michelle is "the big sister now." Lovely drawings illustrate the text.

Fassler, Joan, and Joe Lasker. *Howie Helps Himself*. Morton Grove, IL: Albert Whitman, 1987. Though he enjoys life with his family and attends school, Howie, a child with cerebral palsy, wants more than anything else to be able to move his wheelchair by himself. (P)

Helfman, Elizabeth. *On Being Sara*. Morton Grove, IL: Albert Whitman, 1993. Pointing to symbols on her wheel chair tray is how twelve-year-old Sarah communicates. When she begins her first year in the public middle school, her whole class has to learn her symbols—even the kids who never learned to read before. (P, M)

Holcomb, Nan. *Danny and the Merry-Go-Around*. Hollidaysburg, PA: Jason & Nordic, 1992. Danny, who has cerebral palsy, is faced with another frustrating day at the playground watching the other children play, until a friendly gesture from another kid gives him an unexpected adventure and helps him feel better about himself. (P)

Metzger, Lois. *Barry's Sister.* New York: Atheneum, 1992. At first, twelve-year-old Ellen hates her new baby brother who has cerebral palsy, but as she gets to know him she becomes his strongest advocate. (M, U)

Moran, George. *Imagine Me on A Sit-Ski!* Morton Grove, IL: Albert Whitman, 1995. Billy who has cerebral palsy, use s a wheelchair and symbol board spends tow days at a ski resort where he learns how to go downhill skiing on a sit-ski. (P)

Nixon, Shelly. *From Where I Sit: Making My Way with Cerebral Palsy.* New York: Scholastic, 1999. The autobiography of a young woman with CP. She writes candidly about her feelings, teasing, physical therapy, and speech therapy. (U)

Perske, Robert. *Don't Stop the Music*. Nashville: Abingdon Press, 1986. A journalist becomes involved with two young people who have cerebral palsy. (U)

Wanous, Suzanne. *Sara's Secret*. Minneapolis: Carolrhoda Books, 1995. At first Sara doesn't want anyone at her new school to know about her younger brother Justin, who has cerebral palsy. (P)

Books for adults

Geralis, Elaine, ed. *Children with Cerebral Palsy: A Parent's Guide.* Kensington, MD: Woodbine House, 1991. A comprehensive reference for families of children with cerebral palsy. It contains information about the child's needs in health care, home care, education, legal rights, and long-term care.

Leonard, Jane Faulkner, Margaret Myers, and Sherri Lynn Candenhead. *Keys to Parenting a Child with Cerebral Palsy* (Barron's Parenting Keys). Hauppauge, NY: Barron's Educational Press, 1997. The everyday experience of raising a child with cerebral palsy is spelled out here with advice on helping the child become as independent as possible, providing education and occupational training, and making provisions for the child's social, emotional, and financial future.

Miller, Freeman, and Steven J. Bachrach, M.D. *Cerebral Palsy: A Complete Guide to Caregiving.* Baltimore: Johns Hopkins University Press, 1998. Provides an overview of CP and explains the medical and psychological implications of associated conditions. Includes resources and recommended reading.

United Cerebral Palsy of Minnesota. *Health Care Coverage and Your Disabled Child: A Guide for Parents.* This booklet answers many questions parents might have about health care coverage for their children. It describes types of insurance, HMOs, and alternative ways to finance health care.

Videos

If I Can't Do It. Boston: Fanlight, 1998. This video is a picture of Arthur Campbell, a man with cerebral palsy who was kept at home for 38 years, who later was able to live independently and become active in the disability rights movement. (57 minutes)

National organization

United Cerebral Palsy Association
1660 L St. NW, #700
Washington, DC 20036
(202) 776-0406
www.ucp.org

Spina Bifida

Spina bifida (spy-nuh bih'-fih-duh) is a congenital defect. Literally, it means "spine split in two." One or more of the spinal vertebrae fail to close completely, leaving an opening in the spine. While the cause is not known, it appears to be a combination of environmental and genetic factors.

Myelomeingocele, the most common and serious form of spina bifida, causes lasting effects for the child. The spinal cord protrudes through the opening in the spine, often forming a sac. (The opening is surgically closed shortly after birth.) Since this opening usually occurs at the lower end of the spinal cord, control of the legs, feet, bladder, and bowels can be affected in varying degrees. These can range from mild weakness to complete paralysis.

Eighty percent of children with this form of spina bifida develop hydrocephalus, "water on the brain," which requires a shunt surgery usually the first week after birth. This procedure drains cerebral spinal fluid from the brain and maintains normal pressure.

The resulting disability varies with each individual. Some children with spina bifida have little or no disability. Others have varying degrees of paralysis of the legs and incontinence (lack of bladder and bowel control), which can sometimes be helped through surgical devices. Cognitive and learning difficulties can occur from the hydrocephalus.

Parents and teachers need to check for skin or pressure sores on children with paralysis, since the child has no sensations in the buttocks and lower extremities and spends long hours in braces or wheelchair. Also important in the child's life is a good understanding of psychosocial concerns presented by the disability.

Education requires adaptations for physical needs, but when the child has good use of the upper body, other modifications are minimal. Educators should be aware of the possibility of learning problems secondary to the hydrocephalus. Children with spina bifida often have a good vocabulary and verbalization but difficulty with comprehension.

Hydrocephalus

What is hydrocephalus?

Hydrocephalus is too much cerebrospinal fluid (CSF) in the brain. CSF is normally found in the ventricles (spaces in the brain) and around the spinal cord. With hydrocephalus, the ventricles get bigger than normal, making the head larger. A child can get hydrocephalus if the body produces too much CSF or if the flow of the fluid is blocked.

How is hydrocephalus diagnosed?

Tests that can be done to check for hydrocephalus include:

Ultrasound. High frequency sound waves outline the size of the ventricles.

Computerized tomography scan (CT scan). A computerized scanner records pictures of ventricles.

What is the treatment?

The most effective treatment for hydrocephalus is a shunt. The shunt is a tube that directs the flow of CSF from the ventricles to another place in the body, where it can be absorbed into the bloodstream. It eventually leaves the body through the kidneys.

Surgery is needed to put the shunt in place. There are two types of shunts:

(1) A **VP shunt** (venticulo-peritoneal) moves CSF from the ventricles to a space in the peritoneal cavity inside the abdomen.

(2) A **VA shunt** (ventriculo-auricular) moves CSF from the ventricles into the atrium (top chamber in the heart) through a vein in the neck.

Feelings about a child with spina bifida

For six years, since my daughter's birth, I have been experimenting with various methods of explaining Jill's differences to nieces and nephews, neighbor children, and most recently, classmates. Perhaps some of my experiences can be helpful.

Whenever possible, I think the child with spina bifida should answer questions and give explanations about herself with assistance from adults when needed. Very often people ask me questions about Jill even when she is present. By directing the question back to Jill, the focus becomes Jill, as a person, rather than an object to be talked about. Answering questions about herself is not difficult for Jill now, although she is extremely brief and to the point: "I use a wheelchair because I can't walk. My legs don't work. It was that way when I was born."

I've found that short, nonmedical explanations are best. Of course, terminology should be varied depending on the student's age.

For young elementary-aged children, my explanation has been: "Jill was born with a hole in her back. The doctors fixed it but her legs still don't work. So, she uses a wheelchair to get around."

For older elementary children who especially seem to want (or need) more details, I elaborate: "Jill was born with a hole in her spine. The doctors repaired it, but nerves that should have gone to the muscles in her legs didn't make it past the whole. Without nerves, the muscles don't work, so Jill's legs can't hold her up for standing or for walking. She is paralyzed from her waist down and uses her wheelchair to get around."

In my experience, these brief explanations are very satisfactory for most children. Lengthy, medical conversations are sometimes frightening, often boring, and almost always more than anyone wants to know.

One thing children of all ages seem to be interested in is Jill's wheelchair. When starting kindergarten last year, Jill's teacher had her "show and tell" about her chair: the wheels, the brakes. She stressed that it isn't a toy, and that Jill works it very well by herself and should be asked if she'd like a push. Some children seem to benefit from actually using Jill's chair, and since she isn't bothered by this, we allow it when it seems appropriate.

An attitude that I believe causes some difficulty for children is differentness—I would like to see equal emphasis placed on the sameness of all children. Maybe my daughter said it best when I asked her recently what would be some important things I should say when describing her:

- I have curly hair that's too short for barrettes.
- My favorite color is green.
- I'm six years old.
- I have a baby sister.
- I go to school every day.
- I hate worksheets when they're hard.
- I take swimming lessons at the Y.
- My favorite thing to do is play with friends.
- I love chocolate pudding.

The information about spina bifida was written by Christy Bateman, a member of PACER's Advisory Board and Dr. Ronald Bateman, a former PACER Board member. Both are parents of Jill.

Resources

Books for children

Lutkenhoff, Marlene, and Sony G. Oppenheimer. *Spinabilities: A Young Person's Guide to Spina Bifida*. Bethesda, MD: Woodbine House, 1997. A guide to coping with the medical, self-care, and emotional issues of spina bifida, with an emphasis on becoming as independent as possible. (U)

Nan, Holcomb. *Patrick and Emma Lou*. Hollidaysburg, PA: Jason & Nordic Publishing, 1989. In this storybook, three-year-old Patrick becomes discouraged using his new walker, until a new friend, six-year-old Emma Lou who has spina bifida, helps him discover something important about himself. (P)

Rabe, Bernice. *The Balancing Girl*. New York: Dutton, 1993. Nine-year-old Margaret, who has spina bifida, has a special talent for balancing things, which helps make the school carnival a success. The book is out of print, but check your library for a copy. (P, M)

Rabe, Bernice. *Margaret's Moves*. New York: Dutton, 1991. Ten-year-old Margaret longs for a new, lightweight "sportsmodel" wheelchair so that she can speed around as fast at the athletic brother with whom she has an ongoing rivalry. The book is out of print, but check your library for a copy. (P, M)

Springer, Nancy. *Colt.* New York: Puffin, 1994. In this award-winning book, Colt, who has spina bifida, reluctantly agrees to participate in a special horseback riding program for the disabled. (M)

Books for adults

Minnesota Department of Health. *Guidelines of Care For Children With Special Health Care Needs—Spina Bifida.* Minneapolis: MDH, 1999.

Rowley-Kelly, Fern L., and Donald H. Reigel. *Teaching the Student with Spina Bifida.* Towson, MD: Paul H. Brookes Publishing, 1992. A comprehensive guide for educators working with kids with spina bifida in the regular classroom, full of practical ideas and tips. Sections address education as it's related to health, individualized education, intervention, and social and emotional supports for children and their families.

Sandler, Adrian. *Living with Spina Bifida: A Guide for Families and Professionals.* Chapel Hill, NC: University of North Carolina Press, 1997. Accurate, accessible and up-to-date, this guide is especially for families and professionals who care for children, adolescents, or adults with spina bifida.

Video

In the Middle. Boston: Fanlight, 1985. Documents the problems and joys of a young girl with spina bifida, along with her parents and teachers, as she is mainstreamed into a Head Start program. (28 minutes)

National organizations

March of Dimes
Resource Center
1275 Mamaroneck Ave.
White Plains, NY 10605
(888) MO DIMES
(914) 997-4764 TTY
(914) 997-4763 fax
www.modimes.org
Provides public information on birth defects and offers free fact sheets on spina bifida.

Spina Bifida Association of America
4590 MacArthur Blvd. NW, Suite 250
Washington, DC 20007-4226
(800) 621-3141
(202) 944-3285
(202) 944-3295 fax
www.sbaa.org
Provides information on all aspects of spina bifida, supports research, and encourages training of professionals. Offers many publications on all aspects of spina bifida and a bimonthly newsletter called *Insight*.

Spinal Cord Injury

Spinal cord injury (SCI) is damage to the spinal cord that results in loss of mobility or feeling. It can occur through trauma (such as falls, car accidents, or gunshot) or illness (such as polio or spina bifida).

According to the National Spinal Cord Injury Association, approximately 450,000 people in the United States live with SCI. There are about 8,000 new spinal cord injuries every year, 82 percent involving males between the ages of sixteen and thirty. These injuries result from motor vehicle accidents (42 percent), violence (24 percent), or falls (22 percent).

SCI causes varying degrees of paralysis and loss of sensation, depending on the severity of the injury and what part of the spinal cord is injured. SCI is classified as *complete* or *incomplete*. A complete injury means that the person has no functioning—feeling or voluntary movement—below the site of the injury. Both sides of the body are affected. An incomplete injury means that the person still has some feeling or movement below the injury. The person may be able to move one limb more than another or may have feeling even in parts of the body that don't have voluntary movement. Incomplete injury is becoming more common as treatments become more sophisticated.

Injury to the spinal cord in the neck area can cause *quadriplegia*, which affects all four limbs as well as some body functions. Very high injuries in the neck can result in trouble breathing, and some people with these injuries use ventilators or pacemakers. Partial or total paralysis for either the upper limbs or the lower limbs is referred to as *paraplegia*. Quadriplegia is slightly more common than paraplegia.

SCI can have other effects as well, such as bowel and bladder paralysis, low blood pressure, inability to sweat below the level of the injury, and chronic pain. Many people with SCI lack skin sensations and feelings of pain in parts of their bodies, which can cause other problems. For example, children with paralysis in the lower extremities cannot feel scalding bath water and could be unintentionally burned; shoes and socks must be fitted and checked carefully to prevent skin damage to the feet.

As recently as fifty years ago, spinal cord injury was considered fatal because of the many complications that result. Currently there's still no cure for SCI, but many medical advances have been made that can lessen the severity of injuries. Research has shown that all damage in SCI does not occur instantaneously. The mechanical disruption happens immediate, shortly followed by hemorrhaging in the damaged area and later inflammation that can further damage the nervous tissue. Researchers have developed new drugs to protect nerve cells following injury, which can lessen the severity of some injuries.

One of the most promising treatments studied by the National Institutes of Health is the steroid methylprednisolone, which has been found to reduce the degree of paralysis when administered in high doses within eight hours of a spinal cord injury.

Spinal cord injuries usually do not affect a child's to learn. Intelligence varies from individual to individual, just as in the general population. However, adjustments can and should be made in the classroom so that it is easier for students with a physical disability to do the work and participate in classroom activities with their peers.

Resources

Books for children

Gorman, Carol. *Chelsey and the Green-Haired Kid.* Boston, MA: Houghton Mifflin Company, 1992. A mystery story about a spunky girl with a spinal cord injury who is in a wheelchair and an enigmatic boy with wild green hair. (M, U)

Kachur, Wanda Gilberts. *The Nautilus.* Minnetonka, MN: Peytral Publications, 1997. A novel about Kathryn, who is injured in a car accident. The story follows her through emergency treatment and a rehabilitation center, and it includes details about medical procedures and therapies used in treating SCI. (U)

Panzarino, Connie. *Follow Your Dreams.* Silver Spring, MD: National Spinal Cord Injury Association, 1995. Kids teach kids about spinal cord injuries, each telling a little bit of their own story. (P, M)

———. *Rebecca Finds a New Way.* Silver Spring, MD: National Spinal Cord Injury Association, 1995. Rebecca hurts herself and has a spinal cord injury. What changes are in store? What's it like to be a kid living with spinal cord injury? Written for and by children with SCI. (P)

Book for adults

Senelick, Richard C., and Karla Dougherty. *The Spinal Cord Injury Handbook for Patients and Their Families*. Washington, D.C.: Heathcare, 1998.

Videos

Not Just Surviving. Boston: Fanlight, 1999. Four women who have been living with spinal cord injury talk about their experiences and what they have found to be the key to living a full life after their accidents: having hope. (40 minutes)

Walk This Way. Boston: Fanlight, 1999. An upbeat video about Ron Bachman, who was born with a congenital birth defect that left him with legs he could not use. Explores Ron's fight to live life on his own terms, despite what some might see as daunting obstacles. (20 minutes)

National organizations

National Spinal Cord Injury Association
8300 Colesville Rd., Suite 5515
Silver Spring, MD 20910
(800) 962-9629
(301) 588-6959
(301) 588-9414 fax
www.spinalcord.org
Offers information and support for people with spinal cord injuries, their families, and professionals. Contact the national organization to get information on local chapters.

National Spinal Cord Injury Statistical Center
(205) 934-3320
Information on statistical data on spinal cord injury.

Duchenne Muscular Dystrophy (DMD)

The term *muscular dystrophy* encompasses a set of diseases characterized by the progressive degeneration and weakening of voluntary muscles. There are many types of muscular dystrophy and people of any age can be affected. The most common form, however, is called Duchenne muscular dystrophy (DMD). It affects only male children, and one in every 3,500 male babies in the United States. There are approximately 10,000 children in the United States with DMD.

DMD is an inherited disease transmitted to a child through a defective gene. The disease is passed from a mother, who is a carrier but does not have the disease, to her sons. Each male child born to a carrier mother has a 50 percent chance of having the disease. Each female child born to a carrier mother has a 50 percent chance of being a carrier herself. Occasionally, a child will develop DMD when there is no prior family history of the disease. These are called "sporadic" cases and are thought by some to be the result of gene mutation.

Symptoms

DMD usually appears between the ages of two and six. Parents may notice that their son is particularly awkward or clumsy. He may tiptoe when walking. As the disease progresses, the child has difficulty getting up from a lying or sitting position. He begins to walk in a waddling gait with his shoulders back and his abdomen protruding. Frequently the child's calf muscles appear to be enlarged because healthy muscle is being replaced by fat and connective tissue.

DMD is progressive with no remissions. The muscle degeneration follows a distinctive pattern—beginning in the feet, legs, and pelvis and moving upward to chest and shoulder muscles. It eventually involves all muscle groups.

Tests for muscular dystrophy

Several clinical tests are used to positively identify the disease:

Electromyogram. This test measures the electrical activity of the muscle. The electrical activity of a diseased muscle is distinctly different from that of healthy muscle. The test is uncomfortable.

Serum enzyme tests. These tests measure the amount of muscle protein in the blood. When muscles are healthy, the blood has relatively little muscle protein. High levels of muscle protein indicate diseased muscle tissue. High levels of the protein creatine phosphokinase (CPK) are one of the most important indicators of DMD. This test can also be used on females to determine the likelihood that they carry the gene. Genetic counseling is advised if the tests are positive.

Muscle biopsy. A small piece of muscle tissue is surgically removed and examined under a microscope. In muscular dystrophy, a muscle protein called *dystrophin* is either missing, deficient, or abnormally formed. This protein can be examined in the muscle sample. Muscle tissue of a person with muscular dystrophy shows abnormal fiber development and the presence of fat and connective tissue.

DNA testing. The reason for the flawed or deficient muscle protein is a flawed gene for dystrophin. A test that involves looking at this gene can be done to diagnose or rule out DMD.

Treatment

Presently, there is no cure for muscular dystrophy, but new research into gene therapy offers hope. No current medication or treatment can stop or slow the progressive degeneration of muscle tissue. Treatment for DMD involves careful monitoring, physical therapy, orthopedic devices, and occasionally, surgery to ensure maximum mobility and independence.

Physical therapy, usually daily stretching of muscles, is used to prevent muscles from contracting. Muscle contracture is caused by the weakening of some muscles and the over-pull of others. Severe contractures cause joint deformity and make walking difficult.

Occasionally, surgery is necessary to release contracted muscles and to give the child more mobility. Another surgery procedure inserts rods alongside the spine to hold the torso erect. This eliminates spinal curves and helps to stabilize the child. It relieves organ crowding and increases the child's stamina because he does not have to expend so much energy holding himself up.

Orthopedic aids such as plastic leg braces, canes, and walkers are usually prescribed as the muscles in the legs deteriorate. These aids help keep the child ambulatory as long as possible. Usually by preadolescence (ages nine to twelve), a child with Duchenne muscular dystrophy uses a wheelchair. As the disease progresses and the pectoral muscles weaken, respiratory equipment and antibiotic therapy are used to facilitate breathing and prevent pulmonary infections. Few people with Duchenne muscular dystrophy live beyond their early twenties.

Education can be a most meaningful part of the child's life. During the early stages of muscular dystrophy, the child should be encouraged to continue in the regular classroom and school programs. Adaptations for school and eventually homebound instruction may need to be considered as the disability progresses. Most students with MD today continue in school to graduate with their class. Some people with muscular dystrophy go on to college or trade schools, work part-time, and seek out independent living opportunities with the aid of a personal care attendant. Young people with muscular dystrophy learn to balance hope for the future with reality.

Research into the disease continues, and promising new therapies are being developed. The most exciting of these involves a gene therapy. Immature muscle cells called *myoblasts*, which normally help repair muscle fibers, have been injected into the mice and fused with muscle fibers. Once inside a fiber, the myoblast nucleus, or core, provided a gene that allowed the fiber to begin producing dystrophin. Dystrophin is a protein that children with muscular dystrophy lack. Donald Wood, director of research for the Muscular Dystrophy Association said, "This is the most exciting approach for human therapy that, in my opinion, has ever come along."

This information was reviewed and updated by Peg Williams, a PACER board member, co-founder of the MD Parent Support Group and parent of a son who died from Duchenne muscular dystrophy, and Pat Adams, who was an original member of PACER in 1977. Pat had two sons who died from muscular dystrophy.

Resources

Books for children

Osofsky, Audrey. *My Buddy.* New York: Holt, 1992. An extraordinary relationship between a boy who has muscular dystrophy and his canine companion. More than just a pet, Buddy enables his young master to do things for himself that other kids take for granted. (P)

Roy, Ron. *Move Over, Wheelchairs Coming Through!* New York: Clarion Books, 1985. The author has interviewed young people who use wheelchairs for a variety of reasons. Muscular dystrophy is one of the reasons. Excellent photographs and interesting text introduce us to seven individuals who lead active lives. (M, U)

Siegel, Irwin M. *Everybody's Different, Nobody's Perfect.* Tucson, AZ: MDA, 1989. Offers straightforward facts and feelings about children who have muscular dystrophy. Available online at *www.mdausa.org/publications/nobody/index.html.* (P, M)

Books for adults

Journey of Love: A Parent's Guide to Duchenne Muscular Dystrophy. Tucson, AZ: MDA, 1999. Provides a variety of information, including sections on medical, social, educational and emotional issues.

Weisman, MaryLou. *Intensive Care.* New York: Random House, 1982. The story of a mother raising her 16-year-old son who has muscular dystrophy. (Video available starring Liza Minnelli.)

Video

Muscular Dystrophy. Washington, D.C.: Films for Humanities and Sciences. Profiles of young people with muscular dystrophy and information on research and treatment. (26 minutes)

National organization

Muscular Dystrophy Association
3300 E. Sunrise Dr.
Tucson, AZ 85718
(602) 529-2000
(800) 572-1717
www.mdausa.org

This comprehensive source of information and research on all types of muscular dystrophy funds research and offers materials for professionals, families, children, and educators. Publishes *Quest Magazine*, a bimonthly magazine containing the latest medical information for clients and parents. Call or visit the Web site to find a local MDA affiliate.

Juvenile Rheumatoid Arthritis (JRA)

Juvenile rheumatoid arthritis (JRA) is a chronic disease that affects as many as 285,000 children in the United States. JRA is an autoimmune disease affecting the body's connective tissue. For some yet-unknown reason, the body produces abnormal antibodies that attack normal body tissue. JRA is characterized by swelling around the joints and body organs.

The cause of JRA is unknown. It is unrelated to climate, diet, or lifestyle. Hereditary characteristics may play a role, but heredity alone does not cause it. The onset is usually between the ages of two and four, although it can occur at any age. It is more common in girls than boys.

Juvenile rheumatoid arthritis usually manifests itself in one of three forms:

Polyarticular JRA. Involves five or more joints, usually the fingers, hands, knees, hips, and ankles, often affecting the same joint on both sides of the body. Forty to fifty percent of children with JRA have this type, which affects more girls than boys.

Pauciarticular JRA. Affects four or fewer joints, usually the large joints, not symmetrically. Occasionally causes inflammation of the iris of the eyes in children, which can become serious if untreated. Thirty to forty percent of children with JRA have this type.

Systemic JRA. Affects both the joints and internal organs. Characterized by frequent, high, spiking fevers; a flat, pink rash; and enlarged lymph nodes. Systemic JRA affects the joints and sometimes causes inflammation in the outer lining of the heart and lungs. The attacks may last for months but then disappear for months or years. Twenty percent of children with JRA have this form of the disease, which affects both boys and girls equally.

Treatment

JRA is an unpredictable disease. At times, it seems to go away completely. This is called a *remission*. A remission can last for months or even years. At other times, it gets much worse. This is called a ***flare-up***. Although there is no cure for JRA, 60 to 70 percent of the children with this disease do not suffer permanent joint damage. The disease often goes into permanent remission after ten years.

Long-lasting inflammation can damage the surface of the joints. Joint inflammation can also affect the growth centers in the bones, causing delays in the child's growth and development. The principal treatment of JRA is to control inflammation and protect joints that have become inflamed.

Anti-inflammatory medication such as ibuprofen and aspirin are important in reducing the inflammation and decreasing the pain of arthritis. Seventy-five percent of children with JRA require no other medication. In very severe cases, doctors may prescribe antimalarial drugs, gold injections, or corticosteioids.

Exercise is essential to children with arthritis. A proper exercise program helps relieve stiffness, maintain flexibility, and prevent joint deformity. Every child with JRA should have an exercise program individually designed by a physiatrist (doctor of physical medicine) or a physical therapist. Although contact sports and those that involve jumping or running for long periods of time must be avoided, there are many activities appropriate for children with JRA. Skating, biking, swimming, and badminton all provide excellent exercise opportunities and do not put undue stress on the joints.

All children with JRA should be encouraged to participate in daily activities and to do as much as possible for themselves to build self-esteem and independence, as well as to keep their joints and muscles flexible.

While exercise is important to maintain a range of motion and muscle strength, children with arthritis should avoid fatigue. Children with JRA frequently require more rest than other children. They may need to sleep later in the mornings and often need a nap or quiet rest time during the day.

Feelings about having JRA

Beryl Hurwitch, who has JRA, talks about her arthritis in *Young People and Chronic Illness: True Stories, Help, and Hope* by Kelly Huegel (Minneapolis: Free Spirit, 1998):

> "Sometimes I feel pretty good and am not really bothered by my arthritis, so I can do things like ride my bike and play tennis. Other times, I have flare-ups and my joints start to hurt and get stiff. The flare-ups don't follow a specific pattern, and I don't always know what brings them on (the weather, overactivity, etc.). I tend to have more problems when it's cold because my muscles contract, aggravating my arthritis. It's hard to say when I'm going to have a flare-up—I can be okay for days, or sometime even weeks, but then suddenly start feeling worse." (p. 86)
>
> "Once in a while, I'd get upset and feel frustrated with myself for not being able to join in. But it doesn't make sense to be angry. I've learned to get over it and accept things the way they are. Now I have a deal with my physical education teacher: I'm allowed to sit out whenever I need to, no questions asked." (p. 85)

This material was reviewed and updated by Ceci Shapland, R.N.

Resources

Books for children

Aldape, Virginia Tortorcia. *Nicole's Story: A Book about a Girl with Juvenile Rheumatoid Arthritis.* Minneapolis: Lerner, 1996. An eight-year-old girl talks about what her life is like with juvenile rheumatoid arthritis. (P)

Kids Get Arthritis Too. Atlanta: Arthritis Foundation, no date. A coloring book that shows children similarities they share with a character named Minnie, a young girl with juvenile arthritis. (To order, call 1-800-207-8633.)

Thiele, Cohn. *Jodie's Journey.* New York: Harper, 1990. Jodie's horse, Monarch, is usually in the winner's circle, which is quite a contrast to what Jodie faces everyday with the onset of rheumatoid arthritis. When brushfires threaten, will she be able to save Monarch or herself? (M, U)

Books for adults

Arthritis Foundation. *Raising a Child with Arthritis: Parent's Guide.* Marietta, GA: Longstreet, 1998. An authoritative guide parents can use to help them confidently take charge when raising a child with arthritis.

Brewer, Earl J., M.D., Angel, Kathy Cochran. *Parenting a Child with Arthritis: A Practical, Empathetic Guide to help You and Your Child Live with Arthritis.* Los Angeles: Lowell House, 1995.

Peterman Schwartz, Shelley. *250 Tips for Making Life with Arthritis Easier.* Marietta, GA: Longstreet, 1997. Practical tips for coping with arthritis.

Tucker, Lori B., Bethany A Denardo, and Judith A. Stebulis. *Your Child with Arthritis: A Family Guide for Caregiving*, 1996. A parent's companion to understanding and effectively dealing with the issues facing an arthritic child, surveying medical implications and the impact of illness on family and in school social situations.

Video

Kid with Arthritis. Washington, D.C.: Films for the Humanities and Sciences. Help for children and their parents in dealing with chronic arthritis. (18 minutes)

National organization

American Juvenile Arthritis Organization
Arthritis Foundation
1330 W. Peachtree St.
Atlanta, Georgia 30309
(404) 872-7100
(800) 283.7800
www.arthritis.org/ajao

Part of the Arthritis Foundation, AJAO advocates for children with rheumatic diseases and their families through education, support, and their work toward improved medical care, and research. Call or write to receive free information or to ask about AJAO's newsletter and other publications.

Multiple Sclerosis

Multiple sclerosis (MS) is a chronic disease of the central nervous system. It attacks the white fatty tissue (myelin sheath), which is the coating around the message-carrying nerve fibers of the brain and spinal cord. The destroyed myelin is replaced by plaques of hardened tissue (sclerosis). When this occurs in multiple places within the nervous system, the result is multiple sclerosis—*multiple* because many scattered areas of the brain and spinal cord are affected, *sclerosis* because sclerosed or hardened patches of scar tissue form over the damaged myelin.

Symptoms of MS are unpredictable. They vary greatly from person to person and from time to time in the same person. Symptoms include fatigue, impaired vision, loss of balance and muscle coordination, slurred speech, numbness or tremors, stiffness, bladder and bowel problems, difficulty walking, short-term memory loss, mood swings, and in severe cases, partial or complete paralysis.

Although approximately two-thirds of those who have MS experience their first symptoms between the ages of twenty and forty, the disease may begin in childhood. It seems to occur at a higher incidence rate in cold climates. MS affects women three times as frequently as men. More than 300,000 Americans have MS, with nearly 200 new cases diagnosed every week.

Multiple sclerosis is not contagious, it cannot be inherited, and it is rarely fatal.

There are no drugs that can cure MS, but there are medications that doctors can prescribe to relieve many symptoms.

Questions asked of people with MS

Q. Is MS hereditary?

A. No. Recent research has helped scientists understand that people may have a genetic susceptibility to MS. However, MS is a complicated disease and a person must also have something to trigger the disease process.

Q. Is MS always progressive? Does everyone with MS degenerate?

A. No. MS is not progressive for all individuals. The symptoms vary greatly from person to person. For many people, symptoms of the disease flare up and then subside. When the disease is active, it is called an *exacerbation*. Symptom-free periods are called *remissions*. Some people have mild symptoms that do not change over time. Some people do experience an increase in symptoms over time. The complete spectrum can range from very mild, to intermittent, to a rapidly progressive form of the disease.

Q. Can people with MS work and have families?

A. Yes! Many people with MS continue in their careers. Some people may need to adjust their jobs, but many people with MS work, play, and have families. Some adjustments to accommodate the symptoms of MS may need to be made.

The material on MS was reviewed and updated by Wendy Brower, former manager of government relations for the Minnesota Multiple Sclerosis Society.

Resources

Books for children

Aaseng, Nathan. *Multiple Sclerosis.* Danbury, CT: Franklin Watts, 2000. (U)

Susman, Edward. *Multiple Sclerosis.* Berkeley Heights, NJ: Enslow, 1999. (U)

Book for adults

Lechtenberg, Richard. *Multiple Sclerosis Fact Book*, 2nd ed. Philadelphia,: F.A. Davis Company, 1995. 235 p, $21.95. This guide for people with MS and their offers an extensive discussion of current drug therapies and a bibliography from the professional literature.

Video

Multiple Sclerosis. Washington, D.C: Films for Humanities and Sciences. Explains the progression of this unpredictable and frequently disabling disease, recommended courses of treatment, and possible effects. It profiles a young business analyst who recently learned that she has MS. (26 minutes)

National organization

National Multiple Sclerosis Society
733 Third Ave.
New York, NY 10017
(212) 986-3240
(800) 344-4867
(212) 986-7981 fax
1-800-624-8236 MS Toll-free Information Line
www.nmss.org

Offers current information on MS and links people with support group. Publishes booklets, brochures, videos, and *InsideMS*, a quarterly magazine for people with MS, their families, and health care professionals.

Brittle Bone Disease

Osteogenesis imperfecta (OI), commonly known as brittle bone disease, is a very rare, inherited condition that begins in the womb. It is often evident at birth or during early childhood, but occasionally not diagnosed until later. It occurs once in every 20,000 live births.

The three main signs of this disease are fragile bones that break very easily, blue sclera in the eyes, and conductive deafness caused by gradual formation of spongy bone tissue in the middle ear.

Children with brittle bone disease are usually smaller than average, have underdeveloped muscles, and must be careful to avoid any activity that may result in broken bones. Laughing and coughing, even a loving hug, could lead to serious injury in a child with this condition. Children with brittle bones may have to spend repeated periods in the hospital or have their limbs in casts.

Amputation

The most frequent causes of the loss of an arm, leg, hand, or foot are from accidents, infections such as gangrene, or diseases such as cancer. However, children are sometimes born without limbs (a frequent birth defect in the 1960s among children whose mothers took the drug thalidomide during the early stages of pregnancy). In most situations, children and adults are fitted with a *prosthesis*, an artificial arm, hand, leg or foot.

With or without an artificial limb, most people with amputations do learn to dress, bathe, cook, drive a car, and participate in most activities and occupations. In school, the child can learn to write, draw, and play games with classmates. Some children are comfortable demonstrating their prosthetic devices and showing how they work.

Educational Programs for Children Who Have Physical Disabilities

Most children with physical disabilities are educated in regular classrooms with their peers who do not have disabilities. Some children whose orthopedic problems are extremely involved or who have multiple disabilities may learn in a special classroom or building equipped for their needs. In either setting, children with motor impairments receive adaptive physical education as a part of their regular school program, as well as related services from various kinds of therapists:

Occupational therapists help students develop eye-hand coordination, fine motor skills (such as cutting, pasting, writing), and self-help skills (such as eating and dressing).

Physical therapists help students develop their large muscles and gross motor skills such as walking, sitting, and climbing. They also offer help with wheelchair, braces, crutches, and other assistive devices.

Music therapists or recreation therapists use music or recreation activities to help the child in overall development. Music and games can help muscles relax, speech and communication flow more easily, and bodily motion occur more spontaneously.

Speech and language therapists, clinicians, or pathologists treat speech and language delays and disorders and work individually with children to help them develop the best possible understandable communication skills.

According to Section 504 of the Rehabilitation Act of 1973, a school district must provide accessible programs for students who have physical disabilities.

When a child who has physical disabilities is in the classroom, teachers need to develop ways for the student to participate in regular classroom activities and establish procedures for helping that child out of the building in a fire drill or other emergency. For example, if the child uses a wheelchair, two teachers or other adults should be prepared to carry the child out of the building when elevators cannot be used. An adult should accompany children who have physical disabilities but are able to walk out of the building.

Independence for Those with Physical Disabilities

Because of difficulties and restrictions in mobility, independence tends to be the major problem confronting most people with motor impairments. All children and adults want personal power and should be encouraged to be as independent as possible. People with orthopedic disabilities, however, are sometimes overprotected and assumed to be less capable.

Independence needs to be interpreted differently for each individual who is disabled, whether child or adult. A child with mild cerebral palsy may be able to do anything without special aids by just allowing extra time for each project. A child with paraplegia may need specific appliances for certain projects: a standing frame to get close to the family car to help scrub it clean, but a wheelchair for sitting again to hose off the suds. A motorized wheelchair may enable an older child who has quadriplegia to navigate independently around the house, yard, and neighborhood.

For adults, the most independent lifestyle many enjoy is living in their own home or apartment, where there may be adaptations. These adaptations allow full accessibility and ease, regardless of the degree of mobility difficulty. Kitchens and bathrooms with wide doors, homes with ramps, door levers instead of handles, and appliances adapted for lower working levels make independent living possible.

Managing one's own lifestyle, coming and going as one is able, means total independence. Various types of public transportation for people who have disabilities and adapted vehicles add to that freedom.

Sometimes another person needs to share the responsibility for daily needs with a person who is physically disabled. In many cases, people who require personal care hire an attendant to assist in taking care of their needs. The attendant's duties can range from assisting the person with a disability in and out of bed, to dressing, preparing meals, and shopping.

Semi-independent living options may include living in a group home where there are several people who have disabilities who need help with personal care and household duties. Or it might include staying in one's family home where parents and siblings assist in the care. No matter which lifestyle is chosen, the real test of true independence is the individual's self-esteem.

Three examples from people at the Center for Independent Living in Berkeley, Calif., clarify the meaning of independence:

> Julie, who uses a wheelchair as a result of polio, majored in journalism in college and now works as a newspaper editor. She loves her work and is good at it. Julie admits that she faced many difficulties in reaching her career goal and is still overcoming obstacles. She has a very definite idea of what it means to be independent: "I want to set my own goals and make the decisions that will affect my life. To me, that's what independence is all about."
>
> Dan, who has quadriplegia and works as a clinical psychologist, has some opinions on these issues: "I need the assistance of an attendant and I can't drive, yet I still feel that I am living an independent life. To me, independence doesn't mean being able to do everything, or not needing other people. I've been able to organize my life in a way that is very satisfying to me. I have a successful career, travel, and enjoy cultural events in my city. I love being with people and have a lot of friends. Sure, I have some limitations, but who doesn't?"

> Eric, a high school student who has speech and hearing disabilities, has a slightly different view of what it means to be independent: "Independence means being fully me. I have a lot of feelings, abilities, and dreams. Independence means freeing what's inside of me and letting it come out. I love to work on cars, and I'm really good at it. When I graduate I want to work as a car mechanic. I also enjoy writing poetry for fun. Because of my speech, I can express myself a lot better in writing. Who knows, some day, I might even write a book! I feel I have a lot to contribute to the world I live in."*

**Reprinted with permission from:* Taking Charge of Your Life: A Guide to Independence for Teens With Physical Disabilities. *Washington, DC:* Closer Look, 1981.

Aids and appliances

For mobility

Canes are available in several types. Those with tripod or four-point bases offer considerably more support than the ordinary cane.

Crutches are familiar to most children. The type with cuffs or hands that encircle the arm (Kenny sticks) or below the elbow (Canadian crutches) add to security of movement.

Walkers with or without wheels are often used to aid mobility and stability in movement.

Braces, mechanical devices made of plastic or metal, not only help facilitate mobility but can also help prevent deformity, hold the body in place, and provide support. Braces come in many sizes, including small ones to aid the ankle and long-leg braces that extend from foot to thigh and may have locks and hinges that allow rigidity for standing and flexibility for walking.

Helmets are worn by some children who have orthopedic disabilities to protect their heads during mobility exercises and other activities.

Wheelchairs are familiar to most children. Equipped with seat belts and brakes, some wheelchairs offer other devices like moveable footrests, cup holders, etc. Electric wheelchairs can be operated by pushing a lever with one finger or a hand. Adaptations can be made for people who have quadriplegia and need many assistive devices. It is very important to properly measure the child for a wheelchair. The parent and child need clear communication with the vendor, therapist and/or physician.

Young children often like to get around on scooter boards, hand-propelled carts, and similar devices.

For classroom and home activities

There are an almost infinite array of devices available to help people with physical disabilities participate in everyday classroom and home activities:

- standing frames
- adaptive chairs
- bolsters and wedges
- lowered tables, counters, and desks
- lap boards
- card holders
- book and pencil holders
- many other tools

For self-care

Many appliances enable people who are physically disabled to tend to their own needs:

- eating utensils such as spoons, knives, forks, plates and cups modified in various ways (large, circular tube-like or built-up handles with particular angles; adaptive or lipped edges on plates)
- electric appliances such as scissors and toothbrushes
- railings in showers, bathtubs, and hallways
- elevated toilets, lowered sinks and kitchen appliances
- reachers
- adaptive clothing such as those with Velcro fasteners or extra-large buttonholes

For communication

Devices such as computers, adaptive telephones, tape recorders, and electronic speech devices expand opportunities.

Computer-assisted communication or augmentative/alternative speech devices are being researched and developed rapidly. For people without the ability to speak, communication boards can help users communicate competently. These aids can be programmed simply and then can be stepped up to full adult vocabulary and technical capacities. They may be accessed by touch, switch, or voice or with a laser beam on a headband. Most are lap-sized. Some can be hooked up to a computer for word printout. Size, capacity, and prices vary.

Bliss boards and other communication boards have printed words or symbols that people who are nonverbal can point to or look at to indicate what they wants to communicate. One method of nonverbal communication is called Bliss symbols.

Nicole, a primary grade student who had unintelligible speech, began by pointing to a series of familiar object photographs (grandma, bed, juice, etc.) She then progressed to more abstract line drawings. She borrowed an augmentative communication device for a year. She no longer needs it, because she can speak without it now. According to her mother, the device, along with speech therapy and home reinforcement, aided her receptive and expressive speech considerably.

Questions children ask about physical disabilities

Q. Why are you in that wheelchair?

A. Because my muscles are not as strong as yours, so I can't walk like you do.

Q. Do you have to sleep in your wheelchair?

A. No, I sleep in a bed just like you do. I roll my wheelchair up close to the bed and then, with some help from Mom or Dad, I lift myself out of the wheelchair and on to the bed. That's called a "transfer."

Q. How do you take a bath?

A. Well, Mom helps me into the tub, and I scrub myself as well as I can. Just before I am ready to have her help me out, she checks behind my ears to make sure I'm clean. I love to be in the water because it helps my muscles relax—you know, like at the swimming pool.

Q. Can you go for a ride in a car?

A. Sure. Mom, Dad, or a friend helps me into the car seat. Then they collapse my wheelchair and put it in the trunk. Neat, huh! Some day we may get a van, and I'll just roll right in on the ramp. My school bus has a lift.

Q. If there were a fire in your house, how would you get out?

A. The fire department has special signs or decals that can be put in windows to indicate there is a person who has a disability in the house. My decal is in my bedroom window, so the firefighters would know where I'm sleeping.

Q. Can you play any sports?

A. Sure, there are lots of sports I can play. I love basketball—there are wheelchair basketball teams (like the Minnesota Rolling Gophers). There are square dance groups for people in wheelchairs that I'd like to try out for when I get older. My dad just found a way to attach a hockey stick to my friend's wheelchair, so he can play floor hockey. I might try that, too.

Q. How do you go up or down stairs?

A. Well, I always look for ramps or elevators first. If the building doesn't have those, I either stay on the ground floor or someone has to carry me and my wheelchair up or down. Our house is all on one floor, and Dad built ramps for the steps at the front door and back door.

Q. If you can't get your wheelchair up to the drinking fountain, how do you get a drink?

A. I use a glass. I have a backpack on my wheelchair. In there I keep a glass, tongs or "reachers" to grab things that are out of my reach: sharpened pencils, extra paper, an extra sweater, and my favorite book—you know, in case I have a long wait for my school bus.

Q. Do you have friends?

A. Oh, yeah, I have lots of friends. Some have disabilities and some don't. Do you have friends who have disabilities and who don't?

Simulation Activities for Physical Disabilities

MUSCLE CONTROL

Age level: elementary
Equipment: masking tape
How to play:

- Have children lie down on the floor, then try to get up without using their heads. Discuss the degree of effort required.
- Have children sit in a small group while the teacher reads a story or leads a discussion. Have students continually keep dropping their heads loosely, and at the end of the story discuss how well they could follow the story line.
- Put a long strip of masking tape on the floor. One at a time, have children close their eyes, spin around several times, open their eyes, and try to walk down the tape line.

EXTRA WEIGHT

Age level: elementary
Equipment: Sandbags with armbands to go around wrists
How to play: Let children attach the sandbags to their wrists and walk around the room three times with arms outstretched, or write at a table with sandbags held over the edge. Discuss how difficult it would be to wear heavy arm or leg braces all the time.

ALL THUMBS

Age level: elementary
Equipment: masking tape, clean heavy socks, raisins or chocolate chips, pudding and a spoon
How to play:

- Have children tape down the fingers of their weaker hand, leaving only the thumb free. Using only that hand, eat raisins or feed a friend pudding. Discuss their reactions to poor motor control.
- Put a couple pairs of heavy socks on children's hands and have them try the same exercise. Discuss reactions.

MODES OF MOTION

Age level: preschool, elementary
Equipment: chalk and chalkboard
How to play: Discuss with the children the many ways people move (walking, crawling, hopping, skating, flying, tiptoeing) and why people move in these ways. Then discuss reasons people have for adapting their modes of motion (such as crawling because they're looking for lost contact lenses, tiptoeing because someone is sleeping, running to escape a fire, etc.).

Have each child choose a "mode of motion" (appropriate for the setting, of course) and use it exclusively for all day or part of a day. Discuss with children their feelings about being able to get around using only one "mode of motion."

NURSERY RHYMES

Age level: preschool, elementary
Equipment: picture books with nursery rhymes
How to play: Discuss various nursery rhymes that the children know and talk about changes that would need to be made if principal characters had certain disabilities.

Example: Jack and Jill

What if Jack's legs didn't work and he used a wheelchair—how would he get a bucket of water from the well at the top of a hill? (Jill could push him up the hill, attach the bucket to the rope, and Jack could lower the bucket into the well by slowly releasing the rope or turning the crank. Also, since Jack was in a wheelchair and Jill would help him down the hill, he wouldn't be likely to fall!)

Example: Humpty Dumpty

What if, when he fell off the wall, he broke one of his legs? What could the King's horses and men do for him? Might he be on crutches awhile?

TRY IT OUT

Age level: all ages
Equipment: aids and appliances that can be secured from rental places or catalogues (These can often be rented or borrowed from hospital equipment supply stores or rehabilitation centers.)
How to play: Bring to the classroom devices used by children and adults who have physical disabilities. Let the children experiment and ask questions. They might also be interested in looking at catalogues of devices and clothing available for children who have disabilities. PACER Center has an Aids and Appliances Rental Tote that can be rented for a charge. Call Count Me In at (952) 838-9000.

This material was reviewed and updated by Maria Anderson, a former Early Childhood Coordinator at PACER Center, who is the parent of a daughter who has a disability.

Resources

Books for children

Chaney, Sky, and Pam Fishe, eds. *The Discovery Book*. United Cerebral Palsy of North Bay, Santa Rosa, CA, 1985. Order from UCP, 959 Transport Way, Petaluma, CA 94952, or call (707) 765-6770. A helpful guide for the world, written by children with disabilities. Chapters on friends, family, feelings, problems, challenges and more.

Labanowich, Stan. *Wheelchair Sports*. Mankato, MN: Capstone, 1998. A series of photo-illustrated books that looks at wheelchair sports, including basketball, field events, road racing, and track events. (P)

Dwight, Laura. *We Can Do It*. New York: Star Bright Books, 1998. Bright and appealing photographs of five children with Down Syndrome, spina bifida, blindness, and cerebral palsy having fun and enjoying ordinary activities at home and at school. (P)

Books for adults

Lifchez, Raymond; Winslow, Barbara. *Design for Independent Living: The Environment and Physically Disabled People*. Berkeley, CA: University of California Press, 1981. These very personal profiles of seven men and women from the community of people with physical disabilities in Berkeley, Calif., where the Independent Living movement began, assess their needs in terms of specific activities such as housing, sleeping, sexuality, grooming, feeding, excreting, gaining accessibility to work and recreation, and eliminating barriers.

Rosen, Fred. *How to Travel: A Guidebook for Persons with a Disability.* New York: Science & Humanities Press, 1997. Encouraging people with disabilities to travel, the book offers tips on dining out, hotel and motel accommodations, renting vehicles, travel agents and travel organizations, and traveling by bus, air, rail, and ship.

Magazines

Sports 'N Spokes
5201 N. 19th Ave., Suite 111
Phoenix, AZ 80515
(602) 246-9426
Magazine published bimonthly. Articles cover wheelchair competitive sports and recreation primarily for those with spinal cord injury, spina bifida, amputation and some congenital defects.

The Exceptional Parent
1170 Commonwealth Ave.
Boston, MA 02134
(617) 730-5800
A consumer magazine for parents of children with chronic conditions. The magazine is published eight times per year. It contains articles that provide practical information and emotional support for families.

Mental Retardation

IDEA regulations define *mental retardation* as "significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance."

Minnesota Special Education Rules use the term *mentally impaired* instead, although the definition is similar: "pupils with significantly subaverage general intellectual functioning resulting in or associated with concurrent deficits in adaptive behavior that may require special education instruction and related services." Another term some people use for this disability is *cognitive impairment.*

In general, someone who has mental retardation has lower mental growth and social development compared to the average growth of most people. A person with mental retardation has difficulty in learning and applying knowledge. Some authorities think that people with mental retardation develop in the same way as people without mental retardation, but at a slower rate. Others think that people with mental retardation have difficulties in particular areas of basic thinking and learning, such as perception or memory. Individuals with mental retardation develop differently in academic, social, and vocational skills—just like people without mental retardation. People with mental retardation are unique individuals with their own strengths and weaknesses.

Causes of mental retardation

According to The Arc, mental retardation can be caused by any condition that impairs brain development before birth, at birth, or during childhood. More than 250 causes have been discovered, but in about one-third of the people affected, the cause remains unknown. The three major known causes of mental retardation are Down syndrome, fetal alcohol syndrome, and fragile X syndrome. Most people with mental retardation are not physically distinguishable from people without mental retardation.

Mental retardation can result from:

- chromosomal abnormalities such as Down syndrome, fragile x syndrome, and others
- genetic disorders of the metabolism
- blood incompatibilities between the mother and the fetus
- maternal malnutrition or infections such as rubella, herpes, and cytomega lovirus
- drugs taken by the mother during pregnancy that affect fetal development—alcohol and illegal drugs, nicotine, and others
- asphyxia (lack of oxygen) at birth or as the result of an accident such as near drowning
- lead poisoning or other environmental toxins
- infectious diseases or viral infections
- diet deficiencies or understimulation

Research shows that some mental retardation can be prevented. Newborn screening can catch conditions such as genetic hypothyroidism and Rh disease, which can be treated. Measles and rubella vaccines have also prevented countless cases of mental retardation.

Teaching children with mental retardation

Children with mental retardation have the capacity to learn, develop, and grow. It's just harder for them to learn and it takes them longer. Many people with mental retardation are productive and full participants in their communities who learn the skills they need to live and work independently. Many other adults with mental retardation live with minimal support and guidance from public or private service agencies.

School districts serve children with mental impairments using a variety of programs. Many students spend most of each school day with a regular education class and receive some special education services for a portion of their day. Since each child is different, schools should develop services that are appropriate for each child's individual needs.

Most special education and related services can be provided within the regular classroom. It is important to remember that children with mental retardation are more like typical children than they are different.

Children with mental retardation learn best when:

- Materials are concrete and discrete as well as interesting and age appropriate.

- Information and directions are presented step by step and reviewed frequently. Verbal information and instructions are accompanied by hands-on tasks to reinforce "learning by doing."
- Reinforcement and prompt, consistent feedback are provided.
- Alternative ways of doing tasks are demonstrated and success is individually defined.
- Teaching takes place in real settings; for example, using real money to buy a soda, not pretend money to buy pretend soda. Whenever possible, children with mental retardation should be taught in the same school they would attend if they did not have a disability, so learning can be reinforced by classmates, friends, and neighbors in their own community.

Some questions and controversies

Several court suits have been brought on behalf of children who were placed in classes for students with mental retardation after being misdiagnosed. Some had been mislabeled because of inappropriate or biased tests (e.g., the tests were not administered in child's primary language or did not take the child's cultural heritage into consideration) or insufficient data (e.g., hearing impairment was not considered).

These suits have raised questions about procedures for identification and placement of students who have mental retardation. Evaluators must ensure that all measures used for assessment are appropriate and comprehensive for the child.

In the past, IQ scores were sometimes the only criteria used to determine mental impairment and were considered a permanent measure of someone's intelligence. Today, researchers recognize that IQ is not necessarily a constant measure, and that in some cases IQ can be increased.

Questions children ask about mental retardation

Corky has mental retardation. He attends a regular school and has art, music, and physical education classes with his classmates. He attends a special education classroom for some of the day. He has participated in the Special Olympics and likes to play baseball. He expresses concern about kids teasing him, which hurts his feelings.

Q. How many people have mental retardation?

A. Because definitions of mental retardation and developmental disabilities vary, so do estimates of the number of people affected by these conditions. According to The Arc, approximately 2.5 to 3 percent of the U.S. population have mental retardation and 1 out of 10 families is directly affected. According to a recent study by the

Institute on Community Integration at the University of Minnesota, an estimated 3.9 million people in the U.S. not living in institutions have either mental retardation, developmental disabilities, or both.

Q. What are the levels of mental retardation?

A. Mental retardation is now grouped into two levels: mild-to-moderate and moderate-to-severe impairments. Nearly 90 percent of all people with mental retardation are only mildly affected and are, in many respects, similar to people without mental impairment. The remaining 10 percent or so who have moderate to severe impairments have difficulties functioning but, especially with early intervention, can live satisfying lives with ongoing support and nurturing.

Q. What is the difference between mental retardation and mental illness?

A. *Mental retardation* is considered a chronic developmental disability that:

- is attributed to a mental or physical impairment
- occurs before age 18
- is likely to continue indefinitely
- results in substantial functional limitations

Mental illness means an organic disorder of the brain or a clinically significant disorder of thought mood perception, orientation, memory, or behavior that seriously limits a person's capacity to function in primary aspects of daily living such as personal relations, living arrangements, work, and recreation.

Simulation activities on retardation

WRITING

Age level: grade 3 and up
Equipment: pencil, paper
How to play: Children with mental impairment work very hard at learning things. This experiment illustrates how hard people who have retardation work at writing. Ask each of the children to write a sentence on any subject, but every word in the sentence must have two syllables. Discuss whether this was hard. What if they had to work this hard to learn everything?

DIRECTIONS

Age level: grade 3 and up
Equipment: none
How to play: Explain that many children who have mental impairment have a hard time learning to follow even a few simple directions. Have the children stand. Tell them the teacher is going to read them a list of directions and then they are to repeat them in order. Give ten or fifteen directions rapidly (e.g., stand, sit, clap twice, touch your head, touch your knee, jump, etc.).

Perhaps only a few children should try this while the others watch. Talk with the children about

- below average language ability
- below average ability to generalize and conceptualize
- play interests younger than those of peers

PIRATES SEARCH FOR TREASURE

Age level: grade 4 and up
Equipment: paper, crayons, pencils
How to play: Some children with mental retardation cannot read at all. Discuss what difficulties that would present in playing some games. Have the children pretend that they are pirates and need to follow a map to find a treasure. One of their friends who will participate is mentally retarded and can't read. How could they make the map so everyone could read it?

MITTEN GAME

Age level: grade 4 and up
Equipment: mittens or tape and puzzles
How to play: Some people with mental retardation have trouble making their fingers do what they want them to do. Have several children put on mittens or tape some of their fingers together and try to do a puzzle.

This information on mental retardation was reviewed and updated by Karen Trudell, formerly of ARC of Minnesota, and Marge Goldberg, former codirector of PACER Center.

Resources

Books for children

Booth, Zilpha M. *Finding a Friend.* Mt. Desert, ME: Windswept House, 1996. Mike has Down syndrome. He's also a hero, rescuing his good friend and giving other children some real insights into what it's like to have mental retardation. (P, M)

Byars, Betsy. *The Summer of the Swans.* New York: Puffin Books, 1981. In this wonderful classic novel, 14-year-old Sara discovers how she really feels about Charlie, her little brother with mental retardation, when he gets lost in the woods. Several chapters are written in Charlie's voice. (U)

Haines, Sandra. *Becca and Sue Make Two.* Boise, ID: Writers Press, 1995. A story for children about the friendship between two girls, one of whom has Down syndrome. (P)

Holcomb, Nan. *How about a Hug?* Hollidaysburg, PA: Jason & Nordic Publishers, 1992. A typical day in the life of a little girl with Down syndrome. (P)

Perske, Robert. *Show Me No Mercy.* Nashville, TN: Abingdon Press, 1984. A father struggles to overcome his injuries after being paralyzed in an accident that killed his wife and child and left his son Ben, a 16-year-old with Down syndrome, in danger of being institutionalized. (U)

Rabe, Berniece. *Where's Chimpy?* Morton Grove, IL: Albert Whitman, 1991. This charming book tells the story of Misty and her daddy at bedtime when she discovers her favorite stuffed monkey is missing. A simple story with extraordinary color photographs. Down syndrome is incidentally described in an introductory page. (P, M)

Books for adults

Blatt, Burton. *The Conquest of Mental Retardation.* Austin, TX: Pro-Ed, 1987. Check your library for this recommended and influential book on the subject, now out of print.

Buck, Pearl S. *The Child Who Never Grew.* Bethesda, MD: Woodbine House, 1992. New release of Buck's inspiring account of her struggle to help and understand her first child, a daughter with mental retardation (PKU). Story originally appeared in *Ladies Home Journal* in 1950.

Dougan, Terrell, Lyn Isbell, and Patricia Vyas. *We Have Been There.* Nashville: Abingdon, 1983. Guidebook for parents is a compilation of personal accounts: laws, concerns of siblings, organizations, the service system, and feelings.

Kingsley, Jason, Mitchell Levitz, and Andy Bricky. *Count Us In: Growing Up With Down Syndrome.* Orlando: Harvest Books, 1994. This unique and powerful account of life by two young men with Down syndrome draws from more than 50 conversations between Jason and Mitchell over the course of three years, that touch on such topics as careers, friendships, school, sex, marriage, politics, finances, and independence.

Smith, Romayne. *Children with Mental Retardation: A Parent's Guide.* Bethesda, MD: Woodbine House, 1993. This gives parents the knowledge and confidence they need to help their child and family and regain control of their lives.

Stray-Gunderson, Karen. *Babies with Down Syndrome: A New Parents' Guide*. Bethesda, MD: Woodbine House, 1986. Highly recommended book with chapters by both parents and professionals.

Trainer, Marilyn. *Differences in Common: Straight Talk on Mental Retardation, Down Syndrome, and Life*. Bethesda, MD: Woodbine House, 1991. Lively and poignant essays written by the mother of a son who has Down syndrome.

Videos

As I Am. Boston: Fanlight, 1990. Three young people with developmental disabilities speak about their lives, their problems, and their hopes and expectations for the future. (20 minutes)

Just Friends. Syracuse, NY: Program Development Associates, 1999. Explores how a relationship with a person that has an intellectual disability can help lead that person to a sense of belonging and out of social isolation. (22 minutes)

Step by Step: Heather's Story. Syracuse, NY: Program Development Associates, 1999. Follows Heather, an eight-year-old girl with Down syndrome through two years in a special education classroom and fourth grade in the regular classroom. (65 minutes)

Educating Peter. Syracuse, NY: Program Development Associates, 1999. The story of a boy with Down syndrome and his classmates during the school year in Mrs. Stalling's third grade class. (30 minutes)

Passion for Justice. Boston: Fanlight, 1994. Bob Perske is a crusader for the legal rights of people with developmental disabilities and has handled cases in which such people have been convicted of crimes they did not commit. (30 minutes)

Raymond's Portrait. Boston: Fanlight, 1999. Raymond Hu is an accomplished artist who was born with Down syndrome. This moving documentary looks at what can happen when a child is encouraged to develop to his full potential. (30 minutes)

National organizations

American Association on Mental Retardation
444 N. Capitol St.
Washington, DC 20001-1512
(202) 387-1968
(202) 387-2193 fax
www.aamr.org
Funded in 1876, AAMR is an international multidisciplinary association of professionals. AAMR has had responsibility for defining MR since 1921.

American Association of University Affiliated Programs for Persons with Developmental Disabilities
8630 Fenton St., Suite 410
Silver Spring, MD 20910
(301) 588-2842 (TDD)
(301) 588-8252
www.aauap.org
The AAUAP is a national network of programs providing interdisciplinary training, services to children and adults with developmental disabilities and chronic illnesses, research in mental retardation and developmental disabilities, and disseminating research results.

The Arc
National Headquarters
1010 Wayne Ave., Suite 650
Silver Spring, MD 20910
(301) 565-3842
(800) 433-5255 toll-free
info@thearc.org
www.thearc.org
The Arc (formerly Association for Retarded Citizens of the United States) is largest voluntary organization in the United States committed to the welfare of all children and adults with mental retardation and their families.

National Down Syndrome Congress
7000 Dunwoody Rd., Building #5, Suite 100
Atlanta, GA 30328-1662
(770) 604-9500
(800) 232-NDSC
(770) 604-9898 fax
http://members.carol.net/ndsc
NDSC offers support and empowerment to people with Down syndrome and their families.

National Down Syndrome Society (NDSS)
666 Broadway
New York, NY 10012
(212) 460-9330
(800) 221-4602
www.ndss.org
NDSS continues to increase public awareness about Down syndrome and discover its underlying causes through research, education and advocacy.

National Fragile X Foundation
P.O. Box 190488
San Francisco, CA 94119
(510) 763-6030
(800) 688-8765
www.fragilex.org
Education, research, and advocacy for people with fragile X, their families, and professionals.

National Tourette Syndrome Association
4240 Bell Blvd.
Bayside, NY 11361
(718) 224-2999
(800) 237-0717
tsa.mgh.harvard.edu
National organization that disseminates up-to-date information on Tourette syndrome.

TASH—Disability Advocacy Worldwide
29 W. Susquehanna Ave., Suite 210
Baltimore, MD 21204
(410) 828-8274
(410) 828-6706 fax
www.tash.org
International research, education, and legal advocacy for people with disabilities.

Learning Disabilities

Learning disabilities is the category that serves the largest number of students who receive special education. According to IDEA, learning disabilities involve "a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations, including conditions such as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia." The definition specifically does *not* include "learning problems that are primarily the result of visual, hearing, or motor disabilities, of mental retardation, of emotional disturbance, or of environmental, cultural, or economic disadvantage."

By definition, children with learning disabilities (LD) are average or above average in intelligence but they have a severe discrepancy between their achievement and intellectual ability in one or more academic areas.

Students with LD may have problems learning to read, write, spell, compute, or listen. They may also have difficulty expressing their thoughts verbally or in writing. Some of the specific disorders that are considered learning disabilities include:

Dyslexia. Difficulty learning to read. It may involve several different factors including reversals, substitutions, confusion of symbolic meanings and others.

Dysgraphia. Difficulty writing, including penmanship and spelling difficulties.

Dyscalcula. Difficulty with mathematics.

Perceptual disorders. A message from one of the senses is not received and/or interpreted properly by the brain. A *visual perception disorder* might include reversals or an inability to distinguish differences between shapes. *Auditory perception disorders* include problems in discriminating words, comparing them with other sounds, and making the sound blendings so essential to learning to read. Auditory perception difficulties may be a factor in spoken language problems. Often children with perceptual disorders do not grasp the entire meaning of a spoken or written message. They may not pick up facial expressions or body language.

Some characteristics seem to be displayed more frequently by children with learning disabilities than by other children. No one child has all of these characteristics, but the following list offers examples of behaviors and some clues for identifying children with learning disabilities:

- **Attention-deficit disorders.** Children with attention-deficit disorders have trouble attending to a specific task. They may be distractible and impulse. Learning disabilities and attention-deficit/hyperactivity disorder (ADHD) are related and often found together, but they are separate conditions. Characteristics of attention-deficit disorders may include *inattention* or *overattention*, inordinate focus on a particular object or idea. (For more on ADHD, see pages 123–127.)

- **Hypoactivity.** Unusual inactivity.

- **Lack of coordination.**

- **Perseveration.** Persistently repeating certain actions or words.

- **Language problems.**

- **Memory disorders.**

- **Uneven skill levels in different areas.**

One characteristic is common to all children with learning disabilities: a significant educational discrepancy between expected achievement (ability, potential) and actual achievement.

Educational methods

It is very important for students with LD to be identified and tested in order to determine exactly where they have difficulty. A comprehensive assessment helps identify the specific learning problems that are causing the severe discrepancy between potential and achievement. Specially trained teachers can provide different types of help depending on the child's needs.

Children with LD often require modifications in classroom teaching methods. Different children have different needs, so any modifications should be carefully tailored to the student's identified educational needs. Some children with LD find it helpful when the teacher provides a designated note-taker, allows untimed testing, reduces written assignments, or modifies the curriculum to better fit their needs.

Special materials and consultation with the classroom teacher can work well for some students. Others benefit from individual tutoring or small group instruction from a resource teacher. In some cases, students with LD spend most of their school day in a special classroom setting.

Many materials are available to help students either learn to compensate for their disorder or learn in other ways.

Many famous people are believed to have had LD—for example, Winston Churchill and Woodrow Wilson. Thomas Edison had a difficult time learning to read and write. He wrote the following letter to his mother at age 19:

> Dear Mother—started the store several weeks. I have growed considerably I don't look much like a boy now—hows all the folk did you receive a box of books from Memphis that he promised to sent them—languages. Your son Al.

Actors Cher and Tom Cruise and Olympic star Bruce Jenner are three people with LD who have been successful in their fields.

Questions children ask about learning disabilities

Mitch has a hidden disability. He has learning disabilities. He has trouble reading, writing, and remembering his spelling words. He tries hard, but he gets frustrated easily. He needs to find other ways to learn and be tested. He feels so bad when he cannot do well. He has many abilities, however. He is very coordinated and loves sports. He knows a lot about bikes and races them. He is captain of the baseball team.

Q. Can people with learning disabilities learn?

A. Absolutely, although they may learn in different ways than other students do. People with learning disabilities have average or above-average intelligence. They can succeed.

Q. Do learning disabilities go away as a person grows up?

A. No, but with help, many adults learn to cope very well. Many successful adults in almost every field of work have learning disabilities.

Q. How can you tell if someone is learning disabled?

A. Because a learning disability is a hidden disability, there are no clearly visible signs. A thorough, comprehensive assessment by a team is needed.

Simulation activities for learning disabilities

READING PUZZLE

Equipment: pencil and paper
How to play: Some children with learning disabilities have a hard time telling one letter from another. Make up ten symbols for words the children can read. Show them the list of symbols along with the corresponding word and give them only a minute or two to study it. Then show the children the symbols in a different order and ask them to write the correct word next to each symbol. Make them hurry.

Talk about how the difficulties they experience may be what it is like for some children learning to read. Ask them how they felt and what would have made it easier for them to learn the symbols. Relate their answers to how people with learning problems need other ways to learn things.

CRAZY WRITING

Equipment: mirrors, pencils, and paper
How to play: To many children with dyslexia, letters do not appear the same as they do to most people. Have the children work in pairs. Have one child write a message and tape it to his or her partner's forehead. That child must try to read it in the mirror.

For another experience, have children try writing a sentence with their nondominant hand.

This material on learning disabilities was reviewed by Barbara B. Sorum, former Parent Advocate, PACER Center.

Resources

Books for children

Banks, Jacqueline Turner. *Egg-Drop Blues*. New York: Houghton Mifflin, 1995. Judge is not doing well in science and now his grade depends on the egg-drop competition he's entered with his twin brother. Will Jury cooperate—and even if he does, will it be enough to earn them a place the competition? In this third book about the "posse" at Plank Elementary School, Judge tells the story of his struggles with dyslexia. (P, M)

Barrie, Barbara. *Adam Zigzag*. New York: Laurel-leaf Books, 1996. This young adult novel tells the story of Adam Brody, a popular boy with dyslexia who struggles to learn to read. He tries to escape his problems through drugs but finally finds help in a special school where teachers understand his problems. (M, U)

Cleary, Beverly. *Muggie Maggie*. New York: Camelot, 1991. In this strong tale by Newbery-winner Beverly Cleary, third-grader Maggie Schultz decides she doesn't want to learn cursive writing—she'd rather print or use the computer. (P, M)

Fischer, Gary, and Rhoda Cummings. *The Survival Guide for Kids with LD*. Minneapolis: Free Spirit Publishing, 1990. This handbook for kids with learning disabilities discusses different types of disorders, programs at school, coping with negative feelings, and making friends. Includes a section for parents and teachers.

Gehret, Jeanne. *The Don't-Give-Up Kid and Learning Differences*. Fairport, NY: Verbal Images Press, 1990. The story of Alex and his struggles at school. His parents encourage him and remind him that he keeps trying one thing after another at home. Kids who learn differently need to try new ways to learn. Positive and beautifully illustrated. (P, M)

Griffith, Joe. *How Dyslexic Benny Became a Star*. Yorktown Press, 1997 A touching account of one youngster's struggle in learning to read and the painful journey that he took to gain self-confidence, self-respect, and tremendous success as a human being, as a student, and as an athlete. (P, M)

Hansen, Joyce. *Yellow Bird and Me*. New York: Clarion Books, 1991. In this sequel to *The Gift Giver*, Doris reluctantly helps Yellow with his studies and his part in the school play and discovers that he has dyslexia. (M)

Janover, Caroline. *The Worst Speller in Jr. High*. Minneapolis: Free Spirit Publishing, 1995. Starting out in seventh grade, Katie Kelso finds herself trying to cope with her dyslexia and form a friendship with a very bright boy at school, while she and her family deal with her mother's cancer diagnosis. (M)

Janover, Caroline. *Josh: A Boy with Dyslexia*. Burlington, VT: Waterfront Books, 1988. Josh struggles to live down the stigma of his learning disability and receive both respect and friendship from his peers. Includes information on the characteristics of dyslexia and a list of organizations that deal with learning disabilities. (M)

Lauren, Jill. *Succeeding with LD*. Minneapolis: Free Spirit Publishing, 1997. Twenty true stories of teens and adults with LD who are role models for success. (M, U)

Stern, Judith, and Uzi Ben-Ami. *Many Ways to Learn: Young People's Guide to Learning Disabilities.* New York: Magination Press, 1999. An honest and accessible look at learning disabilities from a child's perspective, this book offers ideas for coping strategies and understanding. (M, U)

Books for adults

Davis, Ronald D., and Eldon M. Braun. *The Gift of Dyslexia: Why Some of the Smartest People Can't Read, and How They Can Learn.* New York: Berkley, 1997. The authors of this book view dyslexia not as a disability but as a hidden talent and creative way of thinking visually that interferes with decoding written words. They offer strategies for using a multisensory approach to improve reading and writing instruction.

Hallowell, Edward. *When You Worry about the Child You Love: Emotional and Learning Problems in Children.* New York: Simon & Shuster, 1996. The bestselling author of *Driven to Distraction* offers guidance to parents whose child has been identified as having an emotional or learning problem. The book focuses on the emotions involved and helps parents decide when to seek professional help and how to take steps that will help their children manage their emotions and learn.

Rosner, Jermone. *Helping Children Overcome Learning Difficulties.* New York: Walker & Co, 1993. Highly praised by parents and educators, Rosner's classic handbook has sold over 80,000 copies. This revised edition has been extensively updated and expanded to include a wealth of new activities to help children with "enigmatic learning problems"—learning disabilities, dyslexia, attention deficit disorder. Graphs, charts, tests are included.

Learning Disabilities. Third edition. New York: McGraw Hill, 1998. This guide for parents of children with learning disabilities offers practical suggestions for strategies they can use at home and at school.

Smith, Sally L. *No Easy Answers: The Learning Disabled Child at Home and at School.* New York: Bantam, 1995. A parent of a child with LD offers a clear description of learning disabilities and a comprehensive explanation of education law. This book is a wonderful reference.

Vail, Pricilla. *Smart Kids with School Problems: Things to Know and Ways to Help.* NAL/ Dutton, 1998. For the frustrated parents of "Conundrum Kids," bright children whose overall academic performance does not match their intellectual capabilities. Concise and authoritative, this much-needed guide is a welcome resource for parents, and teachers.

Winebrenner, Susan. *Teaching Kids with Learning Difficulties in the Regular Classroom.* Minneapolis: Free Spirit Publishing, 1997. This classic guide offers teachers background information on learning disabilities and the kinds of activities and instructional modifications that can help children with LD succeed.

Videos

Adolescence and Learning Disabilities. Circle Pines, MN: AGC Educational Media. Offers suggestions and techniques for helping students with learning disabilities acquire the skills necessary for survival in school. (25 minutes)

Dyslexia. Boston: Fanlight, 1997. (28 minutes)

The Gift of Dyslexia: Why Some of the Smartest People Can't Read and How They Can Learn. Zephyr. Produced for teachers who want to help children with dyslexia succeed, this video offers practical, field-tested methods and easy-to-follow exercises that allow students to stay focused. (48 minutes)

We're Not Stupid: Living with a Learning Difference. Syracuse, NY: Program Development Associates, 1999. Captures the personal stories of young people from all walks of life who discuss what it's like to live with attention deficit disorder and dyslexia. (14 minutes)

National organizations

Council for Exceptional Children (CEC)
Division for Children with Learning Disabilities
1110 N. Glebe Rd., Suite 300
Arlington, VA 22201-5704
(703) 620-3660 voice
1-888-CEC-SPED toll-free
(703) 264-9446 TTY
(703) 264-9494 fax
www.cec.sped.org
This international professional organization works to improve educational outcomes for students with disabilities and gifted students by advocating for appropriate government policies, setting professional standards and providing professional development.

Learning Disabilities Association of America
4156 Library Rd.
Pittsburgh, PA 15234
(412) 341-1515
(412) 341-8077
(412) 344-0224 fax
www.ldanatl.org
Offers information and referral services and an extensive catalog of publications on LD, ADD, mental health, and related topics. Publishes *LDA Newsbriefs* six times a year.

LD Online
www.ldonline.org
This comprehensive interactive site for parents, teachers, and children offers a wealth of resources, including an online Ask the Expert column, articles, book reviews, and links to resources and other sites.

Speech Impairments

IDEA defines *speech impairment* as "a communication disorder, such as stuttering, impaired articulation, a language impairment, or a voice impairment, that adversely affects a child's educational performance."

The disability category is quite broad. A speech disorder may be part of another disability with a known biological cause (e.g., hearing loss or cerebral palsy). Speech impairment may be the only disability, or sometimes it might be one aspect of a specific learning disability. Many speech and language disorders have no known biological cause and are termed *functional disorders*.

Children who have speech problems represent the second largest group of students receiving special education services in the United States.

Many young children have some speech differences from their peers, and often these differences do not adversely affect their educational performance. When speech differences do seem to interfere with learning progress, however, a professional should assess the child's development.

Types of Communication Disorders

Communication disorders can be characterized by problems in any one or a combination of the following:

Articulation or phonological disorders are problems related to the sounds in a language. Errors might include omissions, substitutions, or distortions of sounds.

Voice disorders are usually identified as significant deviations in pitch, loudness, or tonal quality. A child with persistent hoarseness should be seen by a physician and by a speech/language pathologist. Nasality and denasality are usually the result of muscular or structural problems and often require medical services in addition to speech therapy.

Language disorders include a wide range of problems. *Receptive disorders* relate to a child's understanding of what others say. *Expressive disorders* involve a child's ability to express ideas in words and sentences. Children who have difficulty understanding language usually but not always have difficulty expressing themselves. The reverse is less often true.

Stuttering is a disorder that may cause a child to repeat initial sounds or whole words, to prolong certain sounds, or have a complete block with no speech at all.

The people who see a child regularly can play an important role in deciding whether he or she does have a communication problem that may need special attention. The following questions can be helpful in making a decision about whether or not to seek further help:

- Does the child talk like other children of his or her age?
- Is the child's ability to communicate or to understand what is said so limited that it keeps him or her from participating fully with other children?

This material was reviewed and updated by Eleanor Swanson, a speech pathologist, PACER board member and a life member of Minnesota Speech-Language-Hearing Association.

Resources

Books for children

Kline, Suzy. *Mary Marony and the Snake.* New York: Putnam, 1992. Mary stutters and dreads speaking in class, teased mercilessly by a classmate. (M)

Lester, Helen. *Hooway for Wodney Wat.* New York: Walter Lorraine, 1999. Rodney Rat can't pronounce his Rs and his classmates' merciless teasing have left him shy and miserable. When a new bully comes to class, Rodney comes through in this warm and comic tale. (P, M)

Martin, Patricia. *Memory Jug.* Farmington Hills, MI: Gale Grop, 1996. A family tragedy causes Amaryllis to stop talking, and her sister Mack takes over the job of speaking for her. Mack has a hard time stepping aside when Amaryllis no longer needs her sister to be her voice. (M)

Thompson, Mary. *My Brother, Matthew.* Bethesda, MD: Woodbine House, 1992. Two brothers work through sibling resentments and come to a special understanding despite Matthew's communication problems. (P, M)

Weber, John C. *Coping for Kids Who Stutter.* Vero Beach, FL: The Speech Bin, 1993. Practical advice on managing feelings and communicating for kids who stutter. (M, U).

White, E.B. *The Trumpet of the Swan.* New York: Harper, 1970. Real facts of wildlife and nature blend with delightful fantasy in the charming story of Louis, a trumpeter swan who came into the world lacking a voice and learned to play a trumpet. This is a touching and inspiring story about adaptation and triumph. (All ages)

Books for adults

Eisenson, Jon. *Is My Child's Speech Normal?* 2nd ed. Austin, TX: Pro-Ed, 1997. Covers normal speech development through age four, detailing problems about fluency, voice, and articulation and offering parents ideas for enhancing speech development.

Schwartz, Sue, and Joan E. Heller Miller. *The New Language of Toys: Teaching Communication Skills to Special-Needs Children.* Bethesda, MD: Woodbine House, 1996. A guide on using toys and games to promote language acquisition in an entertaining way. Offers a wide array of strategies helpful for children from birth through age six.

Wicka, Donna K.; Falk, M. *Advice to Parents of a Cleft Palate Child.* Springfield, IL: Charles Thomas Publishers, 1982. The work of professionals is summarized.

Videos

Stuttering. Washington, D.C: Films for Humanities and Sciences, date unknown. A look at the causes of stuttering; its impact on children, teenagers, and adults; and therapies designed to help them. (28 minutes)

National organizations

American Speech-Language-Hearing Association
10801 Rockville Pike
Rockville, MD 20852
(301) 897-5700
(800) 638-8255
(301) 897-0157 TTY
(301) 571-0457 fax
www.asha.org

The professional and scientific association for more than 96,000 speech-language pathologists; audiologists; and speech, language, and hearing scientists in the United States and internationally. ASHA promotes the interests of professionals in audiology; speech-language pathology; and speech, language, and hearing science, and advocates for people with communication disabilities. It offers brochures on communication disorders, information on finding a speech-language pathologist or audiologist, and self-help support groups.

National Center for Stuttering
200 E. 33rd St.
New York, NY 10016
(800) 221-2483
executivedirector@stuttering.com
www.stuttering.com
Offers up-to-date information on stuttering, a toll-free national stutters' hot line, and research into the causes and treatment of stuttering.

National Stuttering Project
5100 E. La Palma, Suite 208
Anaheim Hills, CA 92807
(800) 364-1677
(714) 693-7554 fax
NSPinfo@aol.com
www.nspstutter.org
National self-help organization for people who stutter. Contact the national headquarters to find a local chapter near you or for information on stuttering.

Autism

Under IDEA, *autism* means "a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance."

Autism is usually described as a spectrum disorder, which means that its effects range along a continuum from mild to severe. Specific diagnoses within the autism spectrum include Rett's disorder, childhood disintegrative disorder, autistic disorder, pervasive developmental disorder (PDD), atypical autism, and Asperger syndrome. There are no physiological tests to determine whether a person has an autism spectrum disorder; the diagnosis is given when a child displays a number of characteristic behaviors.

Autism spectrum disorders have an onset in childhood and are characterized by uneven development. Children with autism show a pattern of impairments in several areas of development, including social interaction, verbal and nonverbal communication; and restricted, repetitive patterns of behavior, interests, and activities. Children with autism exhibit a full range of IQ scores, but most have some delays in some areas of mental processing. For example, one child may have advanced physical skills but no speech, another might be able to memorize math facts or dates quickly and yet not be able to read with comprehension.

Autism spectrum disorders often affect speech, language awareness, and nonverbal communication. With effective interventions, many children with autism do develop good, functional language, and most others can develop some communication skills such as using sign language, pictures, computers, or other electronic devices.

Children with autism may find it difficult to relate appropriately to people, events, and objects. For example, many children with autism do not like to be touched or held, even as infants. They may focus on repetitive activities, such as spinning the wheels on a toy car, rocking themselves, repeating words, or flexing their fingers, seemingly ignoring everything else going on around them. Many children with autism disorders insist on specific routines in their lives; if one is changed, even slightly, the child may become very upset and have a tantrum.

Autism is estimated to occur in 15 out of every 10,000 births and is four times more common in boys than girls. It has been found throughout the world in families of all racial, ethnic, and social backgrounds. Most scientists now agree that the causes of autism are biological, not psychological, and that there may be multiple factors involved in its development.

Questions children ask about autism

Max has autism. He's in an inclusive autism program at the school attended by his classmates Mitch and Carmen. Mitch and Carmen have questions and concerns about Max and the other students with autism. When Max becomes frustrated he screams and throws objects. Mitch cannot understand why Max needs so much help, because he excels in reading, music and computers. The teacher helps Mitch and Carmen understand what autism is. Mitch and Carmen come up with ideas to be special friends with Max and the other students with autism. Max helps Mitch with his flash cards for the spelling bee and they make plans to sled together at recess.

Q. Are children with autism deaf?

A. No. Children with autism have limited speaking skills, or they may tune out in order to avoid extra stimulation, which may make them appear to be deaf.

Q. What causes autism?

A. There is no specific known cause. It is widely believed that there is a genetic component and that autism occurs early in gestational development of the brain. However, there may be other contributing factors.

Q. What is autism like?

A. The brains of people with autism work differently than other people's. They may have a hard time learning how to communicate, make friends, and behave. Sometimes people with autism have special skills, however. They may excel at reading, math, art, music, or computers.

Q. Why doesn't he or she like loud noises or being touched?

A. Our brains control our senses. Because people with autism have differences in their brains, they sometimes have different sensitivity to sound or touch. This means that certain sounds, lights, and touch can be scary, uncomfortable, or even painful to a person with autism.

Q. Can people with autism improve?

A. Although there is no cure for autism, with appropriate and early intervention people with autism can improve, sometimes dramatically. Speech therapy and occupational therapy are among the many treatments that help children with autism. Some people with autism will learn to speak and behave much like the rest of the population. Others will never learn to speak or behave appropriately.

A Letter from a Speech Therapist to a Parent

It has been such a joy to watch your daughter's skills blossom over the past two years. There have been so many times I have been amazed at her gains in language, insight, and social pragmatics. I try to tell you about these times, as they are all treasured moments . . . but recently she and I shared such a wonderful moment, I thought I had better put it in writing to you.

We were having dinner last week and waiting for our food to arrive. As we chatted, she asked me how work was going. I told her about a little boy I was testing and that he reminded me of her when she was a preschooler. I explained that he might have autism, and that I was nervous to talk to his parents about it. I wondered if she had any advice for me?

Realizing this was a tough question for any 9 year old, I wasn't expecting much from her answer. She thought about the situation and said, "Don't just tell them he has autism. Tell them some things he might do, like have temper tantrums for no reason." I thought this was a great answer, and we talked about how frustrating those temper tantrums can be. I thought that was the end of the conversation, but your daughter went on: "Tell them that they should go to see a good psychologist." Yes, I agreed that was a smart idea. We continued waiting for our dinner, and after thinking for a little while longer, she said, "Tell them not to be afraid."

With that said, I could feel tears coming to my eyes. I told her that her advice was so good that I had better write it down word for word. Wow. Your family has so much to be proud of—your support, enthusiasm, risk-taking and love have had such an impact on her and on all of us who have the honor of being part of your lives. I'm so happy to be part of "the team"!

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Resources

Books for children

Amenta, Charles A. *Russell is Extra Special: A Book About Autism for Children*. New York: Magination Press, 1993. Written by a doctor who is the parent of a child with autism, this picture book speaks about the realities of autism through loving photos of everyday family times. (P, M)

Gartenberg, Zachary M. *Mori's Story: A Book about Autism* Minneapolis: Lerner, 1998. This picture book is written by the sibling of a child with autism. (P, M)

Katz, Illana, Edward Ritvo, MD, and Franz Borowiz. *Joey and Sam*. Los Angeles: Real Life Storybooks, 1993. A beautifully illustrated storybook that focuses on a family with two sons, one who has autism. The book addresses the boys' similarities and differences as it follows them through daily interactions with each other, parents, and friends. (P)

Lears, Laurie. *Ian's Walk*. Morton Grove, IL: Albert Whitman, 1998. Julie goes for a walk to feed the ducks with her big sister Tara and little brother Ian, who has autism. Julie is annoyed and embarrassed by Ian's behavior, but when her brother wanders off, Julie must try to put herself in his place to find him. (P, M)

Meyer, Donald. *Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs*. Bethesda, MD: Woodbine House, 1997. This book clearly speaks to siblings—many of whom have never met another kid with a brother or sister with special needs—letting them know that they are not alone. (P, M)

Sprecher, John. *Jeffrey and the Despondent Dragon*. Muskego, WI: Special Kids Company, 1997. When Jeffery Sprecher was two and newly diagnosed with autism, his father John made up a bedtime story for him. Years later while discussing the story at a national autism conference, John came to realize that he, perhaps far more than his little son, was the one who, at the time, really needed to hear the tale and the important lessons it held. Today, *Jeffrey and the Despondent Dragon* is the first in an on-going series of "Special Message Books" that weave lessons of life and love that each of us, regardless of our strengths and challenges, can enjoy, value, learn and benefit from. (P)

Thompson, Mary. *Andy and His Yellow Frisbee*. Bethesda, MD: Woodbine House, 1996. A heartwarming book about a boy with autism who displays a fascination for objects in repetitive motion. His classmate Sarah's curiosity about his behavior sets the story in motion. Rosie, Andy's protective sister, supplies background information. (P, M)

Watson, Esther. *Talking to Angels*. San Diego: Harcourt Brace, 1996. This nonfiction, hardcover picture book is a moving tribute to the author's autistic sister, Christa, who sees life in a unique way. (P, M)

Books for adults

Anderson, Elizabeth, and Pauline Emmons. *Unlocking the Mysteries of Sensory Dysfunction: A Resource for Anyone Who Works with or Lives with a Child with Sensory Issues*. Arlington, TX: Future Horizons, 1996. Written by parents of two children with sensory integration dysfunction, this informative resource offers a clear and easy-to-read explanation of the disorder.

Attwood, Tony. *Asperger's Syndrome: A Guide for Parents and Professionals*. London: Jessica Kingsley Publishing, 1998. A comprehensive guide to assist parents and professionals with the identification and treatment of Asperger's syndrome.

Baron, Judy, and Sean Baron. *There's a Boy in Here*. New York: Simon and Schuster, 1992. A boy and his mother report on their experiences with autism. Sean's story is one of very few autobiographical accounts. It gives unusual, exceptionally clear insights into the disability and its manifestations.

Brill, Marlene Targ. *Keys to Parenting the Child with Autism*. Hauppauge, NY: Barron's, 1994. Following chapters on what autism is and how it is diagnosed, the author offers advice on getting organized, identifying resources, working with the therapeutic community, ensuring an appropriate education as defined by law and helping children with autism develop their potential.

Fouse, Beth, Ph.D. *Creating a "Win-Win IEP" for Students with Autism*. Arlington, TX: Future Horizons, 1996. A resource for parents or educators who participate in the IEP process.

Freeman, Sabrina, and Lorelei Dake. *Teach Me Language: A Language Manual for Children with Autism, Asperger's Syndrome, and Related Disorders*. Langley, British Columbia: SKF Books, 1997. A step-by-step how-to manual with 400 pages of instructions, explanations, examples, games and cards that attack language weaknesses common to children with pervasive developmental disorders.

Fullerton, Ann. *Higher Functioning Adolescents and Young Adults with Autism: A Teacher's Guide*. Austin, TX: Pro-Ed, 1996. Provides important insights and practical strategies for teaching and supporting higher functioning students with autism in school.

Grandin, Temple, and Margaret M. Scariano. *Emergence: Labeled Autistic*. New York: Warner Books, 1986. Temple tells the story of her emergence, of how she went from a fear-gripped, autistic childhood to become a successful animal scientist and the leading designer of livestock-handling facilities. An astonishing true story, a chronicle of perseverance, courage, and the loving wisdom of a few adults who saw in Temple what others couldn't.

Grandin, Temple, and Oliver Sacks. *Thinking in Pictures and Other Reports from My Life with Autism.* New York: Vintage, 1996. The continued memoir of Temple Grandin.

Gray, Carol. *Comic Strip Conversations.* Arlington, TX: Future Horizons, 1994. This booklet explains the Comic Strip Conversation method used to help students with autism and related disorders comprehend the exchange of information in a conversation by using simple, colorful illustrations.

Gray, Carol. *The New Social Story Book.* Arlington, TX: Future Horizons, 1994. This edition contains 99 new stories that effectively teach relationships, manners, caring, appropriate behavior, hygiene, managing fears, and much more.

Gray, Carol. *The Original Social Story Book.* Arlington, TX: Future Horizons.1994. While the sequel emphasizes social skills and offers fewer stories to improve functional abilities, this earlier edition focuses more on functional skills and less on social.

Gray, Carol. *Taming the Recess Jungle.* Arlington, TX: Future Horizons, 1994. This short collection of materials designed to simplify the social challenges of recess for children with autism and offers a variety of resources and materials to use to make that time more productive and relaxing for everyone.

Hamaguchi, Patricia McAleer. *Childhood Speech, Language, and Listening Problems: What Every Parent Should Know.* New York: John Wiley, 1995. Written for parents who suspect their child may have some type of communication problem, this book explains what is considered "typical" child development, followed by descriptions of symptoms and characteristics found in various common disorders.

Harris, Sandra L. *Siblings of Children with Autism: A Guide for Families.* Bethesda, MD: Woodbine House, 1994. A guide to understanding sibling relationships, how autism affects these relationships, and what families can do to support their other children as they cope with the intensive needs of a child with autism.

Kranowitz, Carol Stock. *The Out-Of-Sync Child: Recognizirg and Coping with Sensory Integration Dysfunction.* New York: Berkley Publishing, 1996. This guide tells parents how to recognize the problem of sensory integration dysfunction and offers a drug-free treatment approach for children who need help.

Maurice, Catherine, Gina Green, and Stephen C. Luce. *Behavioral Intervention of Young Children with Autism*. Austin, TX: Pro-Ed 1996. This manual is inspired by the research of O. Ivar Lovaas, Ph.D. It provides parents and educators information on early intervention based on the principles of Applied Behavior Analysis, developed by Lovaas.

Oberlander, June R. *Slow and Steady, Get Me Ready*. Fairfax Station, VA: Bio-Alpha, 1992. Written by a veteran kindergarten teacher, this book presents 260 weekly developmental activities using everyday household items. Explicit directions are written in everyday language and brief evaluation follows each activity.

O'Neill, Robert E., et al. *Functional Assessment and Program Development for Problem Behavior: A Practical Handbook*. Albany, NY: International Thomson Publishing, 1997. A resource for professionals working with people who present severe, complex, challenging behaviors.

Quill, Kathleen Ann. *Teaching Children with Autism: Strategies to Enhance Communication and Socialization*. Albany, NY: International Thomson Publishing, 1995. This book's central message is that we must understand how children with autism/PDD think, learn, and organize information about the social and nonsocial world.

Satkiewicz-Gayhardt, Barabra Peerernboom, and Roxanne Campell. *Crossing Bridges: A Parent's Perspective on Coping after a Child is Diagnosed with Autism/PDD*. Largo, FL: Potential Unlimited, 1997. A compassionate, honest guidebook designed to validate parents and children in their many challenges, while providing basic autism information and coping strategies. Written by three mothers of children with autism.

Sewell, Karen. *Breakthroughs: How to Reach Students with Autism*. Verona, WI: Attainment, 1998. Written for classroom teachers, parents, and service and advocacy agencies. It's filled with useful details, practical suggestions, lists of material, and how-to's in managing disruptive behaviors.

Simpson, Richard L., and Brenda Myles Smith. *Educating Children and Youth with Autism: Strategies for Effective Practice*. Austin, TX: Pro-Ed, 1998. This book fills the growing demand for information regarding the treatment of autism.

Videos

Autism. Syracuse, NY: Program Development Associates, 1992. Profiles of four people who are autistic—a girl, a teen, a young adult, and Dr. Temple Grandin—offer a glimpse into they symptoms and treatments. (29 minutes)

Autism: A World Apart. Boston: Fanlight, 1988. This video explore the life of three families, all whom have a member with autism, and what it's like to love and care for them. (29 minutes)

Braking the Silence Barrier. Syracuse, NY: Program Development Associates, 1999. A look at creative technologies for helping people with autism, traumatic brain injuries, and learning and speech disabilities. (56 minutes)

Breakthroughs. Boston: Fanlight, 1997. A special education teacher offers a hands-on approach to reaching and teaching students with autism through a program of early intervention, high expectations, tough love, physical prompting, modeling, and attending to task. (25 minutes)

Dr. Temple Grandin: Visual Thinking of a Person with Autism: Future Horizons, 1999. Temple Grandin, Ph.D., eloquently describes her challenges and offers ideas as to how other people with autism can meet these obstacles and improve their lives. (30 minutes)

Straight Talk About Autism. Syracuse, NY: Program Development Associates, 1999. This two-tape program introduces the issues families face when a member has autism. The first tape looks at early childhood, the second at adolescent issues. (41 minutes)

National organizations

Autism Research Institute
4182 Adams Ave.
San Diego, CA 92116
www.autism.com/ari
A nonprofit organization established in 1967, ARI conducts and disseminates research on the causes of autism and on methods of preventing, diagnosing, and treating autism and other severe behavioral disorders of childhood.

Autism Society of America
7910 Woodmont Ave., Suite 300
Bethesda, MD 20814-3015
(800) 3AUTISM x 150
(301)-657-0881
(301)-657-0869 fax
www.autism-society.org
A national support group for people with autism and their families.

Center for the Study of Autism
P.O. Box 4538
Salem, OR 97302
www.autism.org
The Center provides information about autism to parents and professionals, and conducts research on the efficacy of various therapeutic interventions. All of the information it makes available to the public is included on the Web site.

Other Health Impairments

For children who have medical problems that have a bearing on their academic and extra-curricular participation, a special category called "other health impairments" exists.

IDEA defines *other health impairment* as "having limited strength, vitality or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that (i) is due to chronic or acute health problems such as asthma, attention-deficit disorder or attention-deficit/hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, and sickle cell anemia; and (ii) adversely affects a child's educational performance."

This category of disability has grown rapidly since attention-deficit disorders were added to the definition. In 1991–92, 840 children in Minnesota received special education services under this category. In the 2000–2001 school year, however, 7,840 students received special education services for such health impairments.

Cystic Fibrosis

Cystic fibrosis is an inherited condition that causes the mucous glands (including those in the lungs) to secrete thick, sticky mucous. It results in digestive and breathing problems that severely affect a child's health.

The mucous produced by cystic fibrosis affects the production of digestive enzymes, which break down food in the digestion process. Children take medication to help control these problems.

In the lungs, the mucous interferes with the inhalation transfer of oxygen from the air to the blood and the exhalation transfer of carbon dioxide. Children receive postural drainage therapy (a routine pounding on the chest in such a way as to loosen the mucous) and aerosol therapy. The frequency of these routines depends on the condition of the child.

New research has found that people who have cystic fibrosis lack working copies of the cystic fibrosis gene. This defect leads to the deadly respiratory disease. By inserting healthy genes, the disease symptoms may be reversed.

Juvenile Diabetes

Diabetes is a disease of the pancreas that prevents the body from turning carbohydrates into energy.

People who do not have diabetes digest carbohydrates, turning them into glucose. Then insulin, a hormone secreted by the pancreas, acts on the glucose so the body can use it for energy or store it for later use.

With diabetes, the body cannot either produce enough insulin or properly use the insulin it produces. Excess glucose accumulates in the blood instead of being converted into energy. The glucose then passes through kidneys into the urine. The body must then break down fat for energy, which causes an excess of fatty acids, a by-product of metabolized fat. The excess fatty acids poison the body leading to a condition called *acidosis*. If untreated, this condition causes diabetic coma and death.

Diabetes is classified into two types:

Type I: insulin-dependent or juvenile diabetes is the more severe form of diabetes. It affects 500,000 children and adolescents in the United States. It appears abruptly during childhood or adolescence and develops very rapidly with acute symptoms. It requires immediate medical attention.

Type II: non-insulin-dependent, or maturity-onset diabetes occurs most often in overweight adults over 35 years of age. The onset is slower and the symptoms less acute. In non-insulin-dependent diabetes, the pancreas produces insulin that is not able to work fully. Glucose builds up in the blood and gradually damages many parts of the body. This type of diabetes is treated by diet, exercise, and, if necessary, medication to stimulate insulin production. An estimated 10 million Americans suffer from this form of diabetes.

Causes

Heredity appears to be a factor in juvenile diabetes. A child is more likely to have diabetes if one or both of his or her parents have the disease. However, most experts agree that other, unknown factors may be contributing causes of diabetes.

Symptoms

Juvenile diabetes can strike anytime in childhood or adolescence. The symptoms are very acute. They consist of frequent urination, unusual thirst, rapid weight loss, fatigue, weakness, irritability, nausea, vomiting, and extreme hunger. These symptoms occur very suddenly and demand immediate medical attention.

Treatment

There is no cure for diabetes. Insulin can control diabetes but not cure it. This lifelong chronic disease requires continual management. Before the discovery of insulin in 1921, most children with diabetes lived no more than two years after onset. Insulin has dramatically improved the future for children with diabetes. Very careful diabetes management is individually planned by the child's physician. It includes a diet plan, exercise, and insulin.

For children with diabetes a proper diet is essential to maintain the balance between insulin and food sugar, allowing the blood sugar level to stay within normal limits. A child with diabetes needs a well-rounded diet free of concentrated sweets such as candy, soda pop, and frosting. Concentrated sweets release sugar more rapidly than can be balanced by insulin. Children with diabetes must eat good meals on a regular schedule with snacks in between.

Exercise is very important too. There is a very strong correlation between being overweight and diabetes in adults, indicating that obesity interferes with insulin productivity. Routine exercise helps insulin work and keeps weight down. Children with diabetes can enjoy all of the physical activities that other children do.

Generally, people who develop diabetes later in life can control their diabetes with diet plus medication that stimulates the pancreas to produce more insulin. They do no require insulin injections.

Children with juvenile diabetes, however, almost always require insulin injections to live because they have no pancreatic function. Insulin is not a medication. It is a body hormone secreted by the pancreas. The insulin used to treat diabetes is taken from the pancreas of animals and injected into the child's arms, thighs, or abdomen one or more times a day. By age nine or ten, children have usually learned to give themselves injections.

Balance is the key word in the treatment of diabetes. As long as diet, exercise, and insulin are in balance, the child functions normally. When an imbalance occurs, serious problems result.

Imbalance

Insulin reaction (hypoglycemia) occurs when the blood sugar level is too low. This is caused by too much insulin, too little food, and/or sweating. Symptoms include dizziness, hunger, blurred vision, and pale skin. The onset is sudden. The treatment is to eat some form of sugar immediately, such as fruit juice, sugared soda, or two pieces of hard candy. It is essential that children with diabetes either carry or have access to some form of carbohydrate in the event of an insulin reaction. Generally, children feel better within a few minutes of eating some form of sugar, but occasionally they may need to rest for twenty minutes or so before resuming normal activity. Most insulin reactions can be prevented by taking the right amount of insulin, eating adequate meals at regular times, remembering between-meal snacks, and eating additional carbohydrates before excessive exercise.

Acidosis (hyperglycemia) is the opposite of an insulin reaction. It occurs when the insulin level is too low because of neglected injections, poor diet, or infections. This is a serious condition that can lead to diabetic coma. The symptoms, which come on gradually, include flushed and dry skin, thirst, nausea, vomiting, abdominal pain, and/or a fruity odor to the breath. The treatment is to call a physician to administer the proper amount of insulin. The prevention of acidosis is to take prescribed amounts of insulin, follow the prescribed meal plan, and increase insulin at the time of injection.

Since the balance of insulin and sugar is so critical to proper management of diabetes, tests have been devised to monitor this balance. The best way to check blood sugar is by blood tests. Devices are available for home use to aid people with diabetes in testing their own blood and evaluating their blood sugar level. They either compare the color of a drop of blood with a color chart or use a special meter that evaluates and gives a read-out on the glucose level. Children with diabetes usually test their blood sugar four times each day—before meals and at bedtime. The check can be done by children aged nine or ten, or younger.

Another way to check the blood is to check the amount of sugar in the urine. When blood sugar is high, the sugar in the urine is also high. This test, too, is usually done before meals and at bedtime. However, it is not as accurate and most doctors recommend blood testing.

Diabetes is a serious disease. It can lead to serious eye, nerve, and kidney damage. But most experts agree that careful control of blood sugar levels can prevent or reduce the severity of these complications.

Questions children ask about diabetes

Eric has diabetes. He feels faint and shaky and has an insulin reaction. After drinking some fruit juice and eating some food, he feels better. Carmen and Mitch ask lots of questions.

Q. How can you not eat any candy, cake, or ice cream?

A. I can balance desserts into my meal plan on occasion. I can eat angel food cake, plain yellow cake, and ice cream. I substitute it for a bread or carbohydrate serving and a fat serving. I can eat dessert two times a week. A person with diabetes eats a nutritious diet that everyone should be eating. No one needs to eat all those gooey, rich desserts, anyway. Other desserts that I can substitute include a half a cup of pudding, a plain donut, three small cookies, or one small vanilla soft-serve ice cream cone.

Q. Do you have to take shots every day? How can you stand it?

A. I give myself shots every day, usually three or four times a day in different areas of my body (my thigh, arm, or stomach). It doesn't really hurt. It feels like a pinch. You get used to it.

Q. Eric, don't you hate eating certain foods and taking medicine every day?

A. It's my routine to stay healthy. Most people dislike the strict schedule. But, I'm learning to fit it into my life. As I understand my diabetes, I seem to work it out pretty well. Also, I feel better when I follow my plan and my routine.

Q. What are the myths about diabetes?

A. People seem to think that I need to buy special food, cannot do normal activities, and never eat any desserts. But now you know that's not true.

Resources

Books for children

Loy, Spike Nasmyth, Bo Nasmyth Loy, Janet Silverstein, MD, and Marc Weigensberg, MD. *Getting a Grip on Diabetes: Quick Tips & Techniques for Kids and Teens.* Life as seen from a kid-friendly point of view helps children learn to cope with and manage diabetes in order to live healthy, happy lives.

Mazur, Marcia Levine, Peter Banks, and Andrew Keegan. *The Dinosaur Tamer and Other Stories for Children with Diabetes.* New York, Contemporary Books, 1995. These twenty-five stories work to entertain and ease a child's frustrations about having diabetes. (M)

Miller, Judy. *Grilled Cheese at Four O'Clock in the Morning.* Alexandria, VA: American Diabetes Association, 1988. Scott is a young boy who develops diabetes. In learning to cope, Scott discovers some important lessons about life. (P, M)

Peacock, Carol Antoinette, Adair Gregory, and Kyle Carney Gregory. *Sugar Was My Best Food: Diabetes and Me.* Morton Grove, IL: Albert Whitman and Company, 1998. Eleven-year-old Adair Gregory describes learning, at the age of nine, that he has diabetes. He recounts the enormous changes the condition brought to his life—from pricking himself to test his blood sugar and learning to give himself insulin injections to giving up sweets. The book conveys the effects the illness has had on his family, his struggles with his peers, and his feelings of being different. (M)

Pirner, Connie White. *Even Little Kids Get Diabetes.* Morton Grove, IL: Albert Whitman, 1991. Through illustrations and text, a girl talks about living with diabetes. (P)

Roberts, Willo Davis. *Sugar Isn't Everything: A Support Book in Fiction Form, for the Young Diabetic.* New York: Aladdin, 1991. A detailed fictional description of juvenile diabetes in which eleven-year-old Amy discovers she has the disease, learns to treat it and to deal with her anger, and finally accepts that she *can* live with it. (P, M)

Books for adults

Wysocki, Tim. *The Ten Keys to Helping Your Child Grow Up with Diabetes: A Practical Guide for Parents and Caregivers.* Alexandria, VA: American Diabetes Association, 1997. A pediatric psychologist addresses the psychological, social, and emotional issues that diabetes raises for children in a guide for parents.

Brackenridge, Betty Page, and Richard Rubin. *Sweet Kids: How to Balance Diabetes Control and Good Nutrition with Family Peace.* Alexandria, VA: American Diabetes Association, 1996. Helps families to discover the correct balance and integration of medical concerns and family life.

Rapaport, Wendy Satin. *When Diabetes Hits Home.* Lincolnwood, IL: NTC, 1998. Effective strategies for coping with the curveballs diabetes throws at you.

Siminerio, Linda, and Jean Betschart. *ADA Guide to Raising a Child with Diabetes*, 2nd edition. Lincolnwood, IL: NTC, 1999. Winning ways to help your child cope.

Touchette, Nancy. *The Diabetes Problem Solver: Quick Answers to Your Questions about Treatment and Self-Care.* Lincolnwood, IL: NTC, 1996. Identify, treat, and prevent more than 100 of the most common diabetes-related problems.

The following list of resources was provided by the American Diabetes Association, Minnesota Affiliate, Inc.

American Diabetes Association Complete Guide to Diabetes, 2nd edition. Lincolnwood, IL: NTC, 1996. Everything you always wanted to know about diabetes inside one practical book.

Diabetes A to Z, 4th edition. Lincolnwood, IL: NTC, 1998. Improve your life and live happier and healthier with diabetes.

Haig, B., and P. Moynihan. *Whole Parent, Whole Child: A Parent's Guide to Raising the Child with a Chronic Heart Condition.* Minneapolis: Chronimed, 1989. How to help the child with a chronic health problem lead the fullest life possible. This book is written for families and health professionals who care for children with many different conditions.

Videos

Diabetes: Not So Sweet. Boston: Fanlight, 1998. Explores new approaches to the control and prevention of diabetes, along with stories of people who live daily with the challenges of diabetes. (47 minutes)

Juvenile Diabetes. Boston: Fanlight, 1996. (26 minutes)

National organizations

American Diabetes Association (ADA)
Diabetes Information Service Center
1660 Duke St.
Alexandria, VA 22314
1-800-DIABETES
www.diabetes.org
Works to prevent and cure diabetes and to improve the lives of everyone affected by diabetes. The Web site has many links and a catalog of information.

Juvenile Diabetes Foundation International (JDF)
120 Wall St.
New York, NY 10005
1-800-JDF-CURE
212-785-9500
212-785-9595 fax
info@jdfcure.org
www.jdfcure.com

Works to find a cure for juvenile diabetes and offers a variety of publications and advocacy for people affected by diabetes.

Epilepsy

Epilepsy is a chronic disability that can affect people of all ages. It is not a disease but a disorder of the brain characterized by temporary but recurring seizures in which there are uncontrolled electrical discharges from the brain cells. During the brief time of these electrical discharges, the person's consciousness, behavior, bodily functions, sensations, and motor activity can be altered.

The Epilepsy Foundation of America notes that epilepsy is varied and complex and not everyone is affected similarly. The impact runs the gamut from people who are able to live normal or near-normal lives, to those who are severely impaired by epilepsy and its consequences. At least two million Americans are estimated to have active epilepsy and about 100,000 new cases develop each year, three-fourths of these in children and adolescents.

In most instances the cause of epilepsy is unknown. Since it is not a disease, it is not contagious. Some known causes of a seizure disorder are head injuries, fever, convulsions, and diseases of the brain such as meningitis or encephalitis.

Types of seizures

Seizures differ in frequency and in the type of exhibited behavior. There are more than 40 types of seizures, but the three most common types of seizures are:

Absence (petit mal). Very brief (three to thirty seconds) lapse of consciousness with a blank stare, rapid eye blinking, or eyes rolling upward. The child does not hear or see anything during this lapse. This seizure is frequently not detected because it is over so rapidly and the child resumes activity immediately.

Generalized tonic-clonic (grand mal). The child loses consciousness, falls to the ground, and sometimes lets out a loud cry. The body stiffens (tonic phase) and then begins a rhythmic jerking of all parts of the body (clonic phase). Breathing is labored or may appear to stop, which may cause the child to turn blue. Loss of control of the bladder may also occur. The seizure can last one to three minutes and may be followed by confusion, muscle fatigue, and headache. Only if the child passes from one seizure into another without regaining consciousness or if the seizure lasts more than five minutes and shows no sign of ending should medical help be sought.

Complex partial (psycho-motor). Seizures may last from two to four minutes. Behavior during the seizures varies from person to person, but for any one individual the same behavior regularly occurs. Some common behaviors include staring, poorly coordinated automatic behaviors (such as walking aimlessly around the room), fidgeting with clothes, incoherent or irrelevant speech, and lip smacking.

Safety care

Most seizures can be controlled with medication, which is prescribed by a doctor for a particular person. Different kinds of medication help different kinds of epilepsy. Children and adults can participate in most sports or activities, depending on how well their epilepsy is managed through medication.

However, if some types of seizures do occur, important help can be provided by friends, teachers, or bystanders. For children who have an absence seizure (petit mal), a buddy could be assigned to provide missed information so the child can keep up with the rest of the group.

For someone experiencing a generalized tonic-clonic (grand mal) seizure

1. Clear things out of the way, so the person won't be hurt by banging against or falling on something sharp or hazardous.
2. Place a folded jacket, blanket, or cushion under the person's head for comfort.
3. Do not restrain the person.
4. Don't place anything hard in the mouth—doing so could injure the teeth or jaw.
5. Stay by the person until the seizure is over, talking softly and calmly.
6. Roll the person onto his or her side after the seizure subsides.
7. Call a doctor if there is more than one seizure in rapid succession without full recovery, if a seizure lasts more than five minutes, or if the person is in medical danger.

For someone experiencing a complex partial (psycho-motor) seizures

1. Guide the person away from anything dangerous if he or she is aimlessly walking around.
2. Stay with the person until the seizure is over.

Feelings about epilepsy

The Epilepsy Foundation of America stresses the importance of understanding the social and emotional consequences of epilepsy. For many people, these consequences may be more disabling than the seizures.

"Children with seizure disorders face unique challenges at school. The seizures—or the medication, which prevents them—may affect learning, attention, and memory. Having a seizure at school is socially damaging and, unless handled well by staff at all levels, can permanently mark a child as an outcast . . . when the school community is well informed and supportive, an entirely different outcome is possible." (Epilepsy Foundation, Overview of Education Services, School Alert and First Aid Training)

In the book *Exceptional View of Life* (Honolulu: Island Heritage Ltd.) a person with epilepsy says:

> When I have a seizure and somebody sees it they get scared and wonder what's up. Once when we went on a field trip, the bus left me off and a friend was taking me home. I had a seizure and had to lay down in the driveway. The lady was real scared. She jumped out of her car. She didn't know what to do. I don't want them to get worried, but there's no way I can stop them from worrying.
>
> I'm happy that people care when they see me and try to help me. I love everybody that cares for me—my parents, my teachers, my doctor who is trying so hard to get me well. They have special feelings. In other words, they have love for me. People treat me very kindly, with respect. Sometimes when I'm going to have a seizure, I can't just walk over and tell them. It doesn't really bother me so much. I've done it so many times.

Questions children have about epilepsy

Carmen has a hidden disability. She has had epilepsy since birth. Carmen's friends, even Mitch, never knew about her seizures. He learns that epilepsy is not catching, and it can be controlled with medication. Carmen has not had a seizure this past year, but she remembers what it is like to have had a seizure. She mentions ways a friend can help her if a seizure should occur and reminds her friends that she can do almost anything.

Q. Can I catch epilepsy?

A. No, you can't catch epilepsy because it's not a disease.

Q. Does it hurt?

A. No, epilepsy itself doesn't hurt. But, if I bang against something when I have a seizure, I may get hurt.

Q. Is it scary to have a seizure?

A. Well, when I'm having a seizure, I don't know it—so I'm not scared. But many people seem scared when they see it. I wish this wasn't so.

Q. How did you get it?

A. I don't know how I got it. Mom says I've had epilepsy ever since I was real little. But some people have it as a result of head injuries in car accidents, motorcycle accidents, etc.

Q. Aren't you afraid to go places in case you have a seizure?

A. I used to be, but I love to go places, so I don't worry about it. The medicine I take now helps, and I have very few seizures.

Q. Can you play sports?

A. Sure, as long as I take my medication, I can participate in any sport or game that I want to play. In fact, when I'm 16, if I haven't had any seizures for six months (laws vary from six months to two years in the United States), I can even get a driver's license.

The information on epilepsy was contributed by Sister Ann Vivia Walton of the Comprehensive Epilepsy Program and updated by Janet Mims, clinician nurse, and a former PACER board member representing the Minnesota Epilepsy Group.

Resources

Books for children

Aiello, Barbara, and Jeffrey Shulman. *Trick or Treat or Trouble*. Frederick, MD: Twenty-First Century Books, 1989. Set around Halloween, this story features Brian, who has epilepsy. (P, M)

Landau, Elaine. *Epilepsy (Understanding Illness)* Frederick, MD: Twenty-First Century Books, 1995. (M, U)

Moss, Deborah M. *Lee, The Rabbit With Epilepsy*. Bethesda, MD: Woodbine House, 1989. Lee, a young rabbit, has a seizure while fishing with her grandpa. A doctor examines Lee and tells her she has epilepsy. Different types of seizures are explained. (P)

Pridmore, Saxby, and McGrath, Mary. *Julia, Mungo and the Earthquake*. New York: Magination Press. This is a lively, well-written adventure story of Julia, a young girl with epilepsy, who saves the day at her school during an earthquake. (M, U)

Silverstein, Alvin, and Virginia Silverstein. *Epilepsy*. New York: Harper, 1990. A good introduction for young people. (U)

Books for adults

Freeman, John M., M.D., Eileen P.G Vining, and Diana J. Pilas. *Seizures and Epilepsy in Childhood: A Guide for Parents.* Baltimore, MD: John Hopkins University Press, 1997. Discusses types of epilepsy, medications and their side effects, understanding children with epilepsy, surgical issues, and coping and living with epilepsy. An excellent resource for basic information.

Gumnit, Robert J. *Your Child and Epilepsy: A Guide to Living Well.* New York: Demos Vermande, 1995. Written specifically for the parent of a child with epilepsy.

Marshall, Fiona. *Epilepsy: Practical and Easy-To-Follow Advice (Your Child).* New York: Element, 1999.

Reisner, Helen, ed. *Children With Epilepsy, A Parent's Guide.* Bethesda, MD: Woodbine House, 1988. Helps parents learn about epilepsy and how to cope with it and surrounding issues. This excellent resource is out of print, but your local library may have a copy.

Schachter, Steven C., Montouris, Georgia D., Pellock, John M. *The Brainstorms Family: Epilepsy on Our Terms: Stories by Children With Seizures and Their Parents.* Lippincott-Raven Publishers, 1996. In their own words, these children and parents vividly describe the experiences of handling the crisis of the initial seizure, adjusting to the diagnosis of epilepsy, coping with seizures, managing medications and side effects, and with health care providers, teachers, schoolmates, siblings, and friends.

Wilmer, Andrew N. *Epilepsy: 199 Answers: A Doctor Responds to His Patients' Questions.* New York: Demos Vermande, 1996. A short, straightforward book with common questions arranged by topic. Also includes a list of helpful resources.

Videos

A Question of Epilepsy. Landover, MD: Epilepsy Foundation. People discuss how epilepsy has affected their lives. Discusses various seizures as well as covering first aid techniques. (25 minutes)

Epilepsy: The Untold Stories. Boston: Fanlight, 1994. Focuses on people who experience complex partial seizures, and whose symptoms are frequently misdiagnosed as psychiatric or emotional disorders. (27 minutes)

Epilepsy Is—Program I. Landover, MD: Epilepsy Foundation. Curriculum tool for teachers of children ages five to twelve. Not only defines different seizure disorders, but children speak about how epilepsy has affected their lives. (10 minutes)

Epilepsy Is—Program II. Curriculum tool for teachers of children ages twelve and up. Discusses three seizure types, what they look like and how to respond to them through interview with young adults who have epilepsy. (14 minutes)

Epilepsy in School Children. NES/PD. Produced for educators who may teach children with epilepsy. The film explains the different types of seizure, offers examples of children having seizures and techniques the teachers can use to aid the student if necessary. (27 minutes)

School Planning for Children with Seizure Disorders. Landover, MD: Epilepsy Foundation. Illustrates epilepsy-related problems that may affect learning and how schools and family can be of assistance. (14 minutes)

Understanding Seizure Disorders. Landover, MD: Epilepsy Foundation. Explains seizure disorders in easy-to-understand language, dispels myths about epilepsy as well as contains actual footage of seizures. (11 minutes)

National organization

Epilepsy Foundation of America
4351 Garden City Dr.
Landover, MD 20785
(301) 459-3700
1-800-EFA-1000
Offers pamphlets as well as films and videotapes, and has a computerized epilepsy resource library for research on specific topics.

Attention-Deficit/Hyperactivity Disorder

Attention-deficit/hyperactivity disorder (ADHD) is a disorder that involves low attention span, impulsiveness, or overactivity. ADHD begins in early childhood; the symptoms are generally chronic, occur across situations (e.g., at home, at school, with peers). Children who have been diagnosed as having ADHD may experience a number of cognitive, academic, emotional, social, and physical problems in addition to their primary disorder. These children may have problems with academic achievement, depression, low self-esteem, and forming friendships.

Some experts believe that the signs of this disorder can be identified in early infancy. Infants with a difficult temperament who are excessively active, have poor sleeping and eating habits, and show generally negative moods appear to be at greater risk for later ADHD.

Causes of ADHD

Most children's mental health specialists view the disorder as arising from various sources. Heredity has been the focus of much recent research, although some researchers are investigating other factors, such as environmental toxins or allergic reactions to food additives. Some children from chaotic or abusive home environments can develop symptoms like those of ADHD.

ADHD is one the most common disorders seen by child mental health specialists. Boys diagnosed with the disorder far outnumber girls.

This disorder tends to be chronic throughout childhood; approximately one-third of children with this disorder will continue to show signs of the disorder into adulthood.

Treatment for ADHD

Effective treatment for ADHD is one of the most highly debated issues in children's mental health. Stimulant medication (Dexedrine, Ritalin, and Cylert) can be highly effective for school-aged children diagnosed with ADHD. Medication reduces the hyperactivity, increases attention span, and decreases impulsive behavior in 75 percent of children diagnosed with ADHD, according to some studies. Others argue that behavior management techniques are just as effective as stimulants and safer because they do not produce negative side effects. The best evidence seems to suggest that medication alone generally has little lasting benefit and may fail to produce desirable changes in academic behavior and peer relationships. For this reason, the most frequently offered treatment is medication combined with therapies designed to improve academic skills and interpersonal relationships.

Impact on family

Life with a child who has ADHD may be associated with a number of troubling and conflicting feelings: love, anger, anxiety, grief , guilt, fear, and depression. These feelings are not unusual; most parents find it is helpful to share these feelings with someone else—family, friends, a support group, or some other informal group. Parents need to realize the scope and limitations of their responsibility and learn to take care of themselves as well as their child. Individual, couples, or family counseling may be helpful in providing emotional support and guidance in the child's behavior management.

Feelings about having ADHD as told by a young man with ADHD.

People seem to have more tolerance for disabilities they can see. They wouldn't tell someone in a wheelchair that all she needs to do is stand up and walk. People are also tolerant of mental conditions. A person with mental retardation is not expected to do algebra. We don't tell someone with Alzheimer's who is lost, confused, and scared that all he needs to do is look at a map. Then why are people with ADHD expected to be able to just sit down and focus?

ADHD is a disorder that most people just can't comprehend. People can put themselves in the place of a person in a wheelchair, and everybody knows the feeling of being lost and scared. People don't understand taking forty-five minutes just to get started on homework.

Most people with ADHD try really hard. Success is never taken for granted and is constantly strived for. People don't understand the personal failure of a full day of trying to get something done and ending up with nothing.
A dripping faucet is a distraction to anyone. A person who does not have ADHD will get up and stop the dripping faucet, then return to their homework. A person with ADHD may go fix the faucet with every intention of going right back to the homework, but become distracted and not get back to work for an hour.

This information was prepared by the Research and Training Center on Family Support and Children's Mental Health, at Portland State University.

Resources

Books for children

Gehret, Jeanne. *Eagle Eyes: A Child's View of Attention Deficit Disorder.* Fairport, NY: Verbal Images Press, 1991. Ben seems to struggle in situations that require him to concentrate and to control his behavior. His parents and doctor help him channel his energies to his strengths and find strategies to cope. (P, M)

Gordon, Michael, Ph.D. *Jumpin' Johnny Get Back to Work! A Child's Guide to ADHD/Hyperactivity.* New York: DeWitt, 1991. Helps children understand the essential concepts involved in evaluation and treatment of ADHD. This book tells the story of Johnny, what it's like for him to be inattentive and impulsive, and how his family and school help make life easier for him.

Children find this book amusing, educational, and accurate in its depiction of the challenges that confront them daily. (P)

Gordon, Michael. *My Brother's a World Class Pain: A Sibling's Guide to ADHD/Hyperactivity.* New York: DeWitt, 1992.(P)

Gordon, Michael. *I Would If I Could: A Teenager's Guide to ADHD/Hyperactivity.* New York: DeWitt, 1993. (M, U).

Ingersol, Barbara, Ph.D. *Different Drums, Different Drummers: A Guide for Young People with ADHD.* Cape Publications, 1995. Do people with ADHD have a "deficit" and a "disorder"? Or are they just different in some ways from people around them? This book, written for children and adolescents struggling with ADHD, stresses the value of individual differences. It offers young readers the opportunity to see themselves in a positive light and motivates them to face challenging problems. (P, M)

Janover, Caroline. *Zipper: The Kid with ADHD.* Bethesda, MD. Woodbine House, 1997. Zipper encourages other kids to find ways to manage their behavior, and gives their friends a look at what it's like to have this disorder. (P, M)

Nadeau, Kathleen, and Ellen Dixon. *Learning to Slow Down and Pay Attention.* Annandale, VA: Chesapeake Psychological Publications, 1991. Surveys behavior at school, behavior with friends, self-concept issues, behavior at home, attention focusing at school, homework improvement, morning routines, memory improvement, stress reduction techniques, decision making and problem solving skills, and improving family relationships. It contains separate instructions for parents. (P)

Parker, N. Roberta. *Making the Grade: An Adolescent's Struggle with ADD.* Specialty Press, Inc., 1992. Eager to make a good showing in junior high, seventh grader Jim Jerome finds his problems with self-control and inattention threaten his chances of success in school and in sports. With the help of his parents, teachers, and concerned health professionals, Jim learns about ADD and ways to help himself. Following the story is a section titled "Facts About ADD: Commonly Asked Questions and Answers" which offers more direct information to young readers. (P, M)

———. *Slam Dunk: A Young Boy's Struggle with ADD.* Toby Butler is an inner city fifth-grader who loves basketball and has problems paying attention. He's diagnosed with ADD, which has affected his home and school life. Classroom accommodations and behavioral and medical interventions are described so children can understand them. The story is followed by a Q and A section about ADD by psychologist, Harvey C. Parker, Ph.D. (P, M)

Quinn, Patricia O., Judith Stern. *Putting On the Brakes: A Child's Guide to Understanding and Gaining Control Over Attention-Deficit/Hyperactivity Disorder.* Magination Press, 1995. This book is an honest accessible overview of ADHD, addressing the physiology, medication, symptoms and various supports. The suggested coping strategies attempt to give kids a sense of control and a perception of attainable goals related to ADHD. Each individual can be a powerful force in their own treatment. (P)

Shapiro, L.E., and T. Parrotte, T. *Sometimes I Drive My Mom Crazy, but I Know She's Crazy About Me: A Self-Esteem Book of Overactive and Impulsive Children.* King of Prussia, PA: Center for Applied Psychology, 1993. (P)

Books for adults

Aldridge, E. Jerry, and Anne E. Eddowes. *No Easy Answers: Helping Children with Attention and Activity Level Differences.* Association for Childhood Education International, 1998.

Barkley, A. Russell. *Attention Deficit/Hyperactivity Disorder: A Handbook for Diagnosis and Treatment.* New York: Guilford Press, 1998.

———. *Defiant Children: A Clinician's Manual for Parent Training.* New York: Guilford Press, 1998. For those who provide psychological services to children with ADD, oppositional disorder, conduct disorders, etc. Workbook is included.

Barkley, Russell, and Kevin Murphy. *Attention Deficit Hyperactivity Disorder: A Clinical Workbook.* New York: Guilford Press,1998. This comb-bound workbook provides a master set of the assessment and treatment forms, questionnaires, and handouts recommended by Barkley in *Attention Deficit/Hyperactivity Disorder: A Handbook for Diagnosis and Treatment,* second edition. The book includes a fact sheet for parents and teachers of children with ADHD as well as ADHD diagnosed adults; daily school report cards for monitoring academic progress; and more.

Bloomquist. *A Parent's Skills Training Guide for Children with Attention-Deficits and Disruptive Behavior.* New York: Guilford Press, 1992. Discusses various disruptive behaviors and management strategies.

Flick, L. Grad. *The Complete ADD/ADHD Activities Resource Book: Ready-to-Use Strategies and Techniques for Helping Children with Attention Deficit Disorder.* New York: Prentice Hall, 1998.

Freed, Jeffery, and Laurie Parson. *Right-Brained Children in a Left-Brained World: Unlocking* the *Potential of Your ADD Child.* New York: Simon and Schuster, 1997.

Halowell, Edward, and John Ratey. *Answers to Distraction*. New York: Bantam, 1996. Answers questions about identifying symptoms, diagnosis issues treatment options, day-to-day living, etc.

Ingersoll, Barbara D. *Daredevils and Daydreamers: New Perspectives on Attention Deficit/Hyperactivity Disorder.* New York: Doubleday, 1997. Covering every aspect of dealing with ADHD, including diagnosis, environmental triggers, and associated learning and social disorders.

Reif, Sandra. *The ADD/ADHD Checklist*. New York: Prentice Hall, 1998. Written by one of America's ADD experts, this book is packed with up-to-date facts, findings, and proven strategies for understanding and helping children and adolescents with ADD and hyperactivity.

Multiple Disabilities

IDEA defines *multiple disabilities* as "concomitant impairments (such as mental retardation-blindness, mental retardation-orthopedic impairment, etc.), the combination of which causes such severe educational needs that they cannot be accommodated in special education programs solely for one of the impairments. The term does not include deaf-blindness."

These children present very special needs for their families and educators and may be placed in special classrooms or regular education settings.

Other terms often used by school systems and educators to describe this population of students may include *severely disabled, multiply disabled,* and *severely and profoundly disabled.*

Resources

Book for adults

Lehr, Donna H., and Fredda Brown. *People with Disabilities who Challenge the System.* Baltimore: Paul H. Brookes, 1996. Written for professionals, this book explores the changes in services for children with the most severe disabilities. With real-life accounts of inclusion experiences, the authors describe how those with multiple disabilities can be included in school, in the community, and in the workplace.

National organization

TASH
The Association for Persons with Severe Handicaps
29 W. Susquehanna Ave., Suite 210
Baltimore, MD 21204
(410) 828-6706
www.tash.org
An advocacy group working for the inclusion of all individuals in every aspect of life. Membership includes parents, professionals, and self-advocates.

Laws That Affect Children with Disabilities

The Individuals with Disabilities Education Act (IDEA)

In 1975, President Ford signed into law the Education for All Handicapped Children Act, the landmark legislation that granted children with disabilities legal rights to an education. Until that time, some states required services for some students with disabilities, but many students were not permitted to attend school at all. The law guaranteed students with disabilities the right to an appropriate education and provided their parents with certain rights to participate in developing their child's educational program.

When the act was reauthorized in 1990, it was renamed the Individuals with Disabilities Education Act (IDEA), and in 1997 it was amended again. This resource manual reflects the most recent revisions.

In summary, IDEA states that all children, regardless of disabilities, are entitled to a free, appropriate public education in the least restrictive alternative.

Minnesota, for instance, entitles children with disabilities to a free, appropriate educational program beginning at birth and continuing through completion of high school or age 22.

What disabilities are covered under IDEA?

The disabilities or special needs that are described in special education law include:

- mental retardation
- hearing impairments, including deafness
- speech or language impairments
- visual impairments, including blindness
- emotional disturbances
- orthopedic impairments
- autism

- traumatic brain injury
- other health impairments
- specific learning disabilities
- deaf-blindness
- multiple disabilities

Children may have disabilities that are not visible or obvious, such as attention deficit hyperactivity disorder (ADHD) or depression. If a disability interferes with learning, a child may be eligible for special education services.

The term *developmental delay* is often used for children ages birth to 3. In Minnesota, local school districts may also use this disability category for children ages 3 to 7. If a local district or cooperative chooses to do so, it must use both the definition and the age range defined by the state. In districts that choose not to use the expanded definition of developmental delay, children over 3 have to meet the criteria for one of the disability areas in order to receive services.

In Minnesota, schools are required to serve eligible children from birth until age 22 or the completion of high school, whichever comes first. (This will change on July 1, 2002, to age 21. Students then will be eligible for special education until the July following their 21st birthday.)

The public school district in which the child's parents or guardians reside is financially and legally responsible for that child's special education program and related services. Children with disabilities who attend parochial/non-public schools are also eligible to receive special education services through the public school system. These services are provided at public schools or at neutral sites.

What are special education and related services?

Under IDEA, *special education* means "specially designed instruction, at no cost to parents, to meet the unique needs of a child with a disability." It can be provided in the classroom, home, hospital or institution, or other setting and includes instruction in physical education. These services are provided by licensed personnel and include special teaching materials and techniques. Special education services may also require special equipment or facilities.

Related services are "transportation and such developmental, corrective, or other support services . . . as may be required to assist a child with a disability to benefit from special education." Related services include "speech-language pathology and audiology services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, social work services, counseling services, including rehabilitation counseling, orientation and mobility services, and medical services . . . for diagnostic and evaluation purposes only."

In Minnesota, special education and related services may include direct or indirect services. *Direct services* are those delivered directly to the student by a special education teacher or a related-services professional. *Indirect services* are provided by special education staff to regular education teachers, parents, or others who have direct contact with the student. Indirect services include consultations; ongoing progress reviews; accommodations in the environment, curriculum, materials, or equipment; and monitoring, observing, and reviewing the student's progress.

How are children with disabilities identified?

IDEA mandates that school districts ensure that all children (birth to 21) with disabilities who reside within their jurisdiction and need special education and related services are identified, located, and evaluated. This includes children in all public and private agencies and institutions who live within that jurisdiction, as well as children of preschool age. This process of identifying children with disabilities is often called *child find*.

The importance of good systems for the identification and assessment of young children with disabilities (birth to 3) cannot be overemphasized. By identifying children as early as possible, adults who work with young children may offer help in such a way as to enhance the child's potential and minimize some of the negative effects of the disability. Identifying a child's disabling condition is only the first step in the process of assessing the specific needs of the child and planning an appropriate program.

How are children with disabilities located?

Identification activities can include the use of school census, screening, general public information, and referrals from parents, teachers, doctors, agencies or other interested people.

Census. All school districts in Minnesota (apart from Minneapolis, St. Paul, and Duluth) are required to take an annual school census to identify all children, ages birth to 21, including those who have disabilities.

Screening. Screening refers to a method of identifying possible disabilities by giving children a series of health or educational tests. Examples include tests given at periodic health checkups and pre-kindergarten screenings to check vision, hearing, motor skills, and coordination. Routine screening for vision, hearing, or scoliosis (curvature of the spine) is conducted at various grade levels in elementary schools.

Screenings do not provide enough detailed information to determine that a disability does indeed exist. If a screening indicates a possibly problem, assessment is the necessary next step.

Public information programs. Information about various disabilities through media sources (TV, radio, newspapers, etc.) may help parents and others recognize a disability or particular delay in a child.

Referrals by parents. A parent or other interested person may request that an assessment be arranged for any child. Parents are the primary observers of their child, the ones who see the child daily in many different situations. They are often the first to suspect a problem such as a developmental delay, a hearing problem, a learning disability, or some other disability. A parent may request an assessment for the child at any time a disability is suspected.

Referrals by teachers. Classroom teachers can be important in making referrals because of their daily contact with many students and their ability to recognize a problem which may indicate a student has disabilities. Teachers should be aware of signs that indicate a disabling condition.

Referrals by medical personnel and agencies. Health professionals, especially pediatricians or pediatric nurses, might detect a condition that could warrant special education services. These professionals often encourage the parents to seek out an assessment from the school or from a medical facility, whichever is most appropriate. People in agencies such as Head Start programs, day care centers, group homes, scouts, or park programs may suspect a problem or disability in a child. It is appropriate to discuss the observation with the parent or school, whichever is appropriate, and have the child referred for assessment.

How are children evaluated for special education services?

Each school has its own procedure for referring a child for evaluation whenever a problem is suspected. If a routine screening indicates a potential problem, the school should automatically tell the parents what follow-up is necessary.

If a teacher suspects a disability or need for assessment, the school usually has a referral form that can be completed by the teacher and given to the designated person, often a principal or special education director, before making a referral. Many resources are available to help teachers learn more about disabilities. Schools must obtain parental consent in writing before proceeding with an evaluation.

Sometimes a teacher may find it necessary to initiate the referral process for a particular student even though the school district does not currently have the necessary resources to serve the child. The law is clear: All children with disabilities must be served with appropriate programs. Teachers, parents, and all advocates for children must be concerned if school districts adopt policies that conflict with the law's intent.

When a parent wishes to request an evaluation, the first step is to send a letter to the principal or the special education director, with a copy to the classroom teacher. The letter should include information about the nature of the problem, observations from parents and others, and reasons for wanting an assessment.

The identification and evaluation processes are extremely important if all children with disabilities are to be provided with a free, appropriate, public education. Teachers and parents play a significant role in insuring that all children with disabilities are located, identified and evaluated.

What is an individualized education program?

An individualized education program (IEP) is a written plan for educating a child with a disability. It is developed by a team at a meeting, and its components are based on the results of an evaluation. The IEP describes the educational program and services designed to meet a child's specific needs.

Every child who receives special education and related services must have an IEP. The child's parents must be invited to help develop the IEP and must be given a copy when it is completed. In addition, the IEP must:

- be implemented as soon as possible after the IEP development meeting
- be accessible to the teachers and others who are responsible for putting the program into action
- remain in effect at the beginning of each school year as long as the child needs special education and related services
- be reviewed at least once a year to determine whether the annual goals are being achieved

Because every child is unique, each IEP should be, too. A child's IEP must be based on his or her assessed needs.

For a child ages birth to 3, an Individual Family Service Plan (IFSP) is used instead of an IEP. An IFSP requires that the team look at the concerns, priorities, and resources of the family as they relate to the child's development. Because the IFSP is an interagency document, representatives from education, health, human services, and other private agencies may be involved in developing the plan. The agency responsible for providing each service is determined, and that agency signs the document for that particular service and assumes financial responsibility.

What is the least restrictive environment?

Children with disabilities have been increasingly included in the everyday life of the public school because of IDEA. According to the law, children with disabilities are to be educated, to the maximum extent possible, with children without disabilities. This concept is known as the least restrictive alternative.

In the past, many children with disabilities were separated from their normal peers and kept in special classrooms for children with disabilities throughout their school years. Sometimes the children in these classrooms had similar disabilities, sometimes very dissimilar disabilities, but nonetheless they were segregated from the rest of the school population because of the fact that they had a disability. These children missed many opportunities for learning and development; they were categorized by what they couldn't do rather than by what they could do.

Knowledge and understanding of individuals with disabilities can foster positive attitudes that will enable the *least restrictive alternative* to work, not just in the classroom, but also in the hallways and the neighborhoods, in every walk of life.

Section 504 of the Rehabilitation Act of 1973

Section 504 of the Rehabilitation Act of 1973 is often referred to as a civil rights act for people with disabilities. It protects the rights of people with disabilities by prohibiting agencies and organizations that receive federal funds from discriminating against people solely on the basis of disability.

Under Section 504, students with disabilities are entitled to a free, appropriate public education (FAPE). Schools must provide educational services designed to meet the needs of students with disabilities as adequately as they meet the needs of students without disabilities.

What is a disability under Section 504?

IDEA defines specific categories of disabilities that students must fit in order to receive special education services, but Section 504, like the ADA, defines disability more broadly. Under Section 504, a student is determined to have a disability if he or she:

1. has a physical or mental impairment that substantially limits one or more major life activity (walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, performing manual tasks),
2. has a record of such impairment, or
3. is regarded as having such an impairment.

This can mean that a child who has a disability that does not qualify for special education services under IDEA (such as hepatitis, asthma, or chemical dependency) may still be entitled to accommodations or other educational services in under Section 504.

What are accommodations under Section 504?

Accommodations are designed to make the classroom environment and extra curricular activities accessible to individuals with disabilities. Accommodations must achieve meaningful equal opportunities, consider the functional limitations of the person, and offer alternative methods of performance. Examples of accommodations include modified testing, preferential seating, taped textbooks, readers, tailored homework assignments, and the like.

Are evaluations and individual education programs (IEPs) required under Section 504?

According to the law, the school district must evaluate "any person who, because of handicap, [as defined above] needs or is believed to need special education or related services." Evaluation is required before a significant change in a student's placement. Placement decisions must be based on documented information from varied sources, considering all relevant information. Decisions must be made by a group of people who are knowledgeable about the child, the meaning of the data, and the placement options.

A formal IEP is not required for students receiving accommodations under Section 504. However, a plan describing placement and services must be developed, and putting that plan in writing provides documentation.

What are the responsibilities of schools?

Schools must provide assurance that they do not discriminate, designate an employee to ensure compliance, provide grievance procedures, identify and locate all children with disabilities who are not receiving public education, and provide notice of the district's Section 504 responsibilities and procedural safeguards. Procedural safeguards include:

1. parents' right to notice of action regarding identification, evaluation, and placement of their child with a disability
2. parents' right to review records
3. the right to an impartial hearing
4. the right to a review procedure

The district must give you a copy of your procedural safeguards within the school district also.

What if there appears to be a violation?

Section 504 complaints are investigated by the Department of Education's Office for Civil Rights. You can reach the national office at:

Office for Civil Rights
Department of Education
Switzer Building
330 C St. SW
Washington, DC 20202
(202) 205-5413
www.ed.gov/offices/ocr

The Americans with Disabilities Act

The Americans with Disabilities Act (ADA) was signed into law on July 26, 1990. Like Section 504, it provides civil rights protections to individuals with disabilities that are like those provided to individuals on the basis of race, sex, national origin, and religion. However, ADA protections also apply to private businesses, shopping centers, places of recreation, and other programs, even if they do not receive federal funds.

Employment

- Employment provisions apply to all public services and private employers with 15 or more employees.
- Employers must provide reasonable accommodations for qualified applicants or employees with disabilities unless it would result in undue hardship for the employer.
- Reasonable accommodations include making work sites accessible, modifying existing equipment or providing assistive technology, modifying work schedules, restructuring jobs, and other actions.
- Employers may reject applicants or fire employees who are a direct threat to the health or safety of others.
- Applicants and employees are not protected from personnel actions that are based on the current illegal use of drugs.
- Employers may not discriminate against people who have an association with an individual known to have a disability. For example, employers cannot discriminate against parents who have a child with a disability.
- Individuals may file complaints with the Equal Employment Opportunity Commission.

Public services: state and local government, including public schools and public transportation

- Public services may not discriminate against individuals with disabilities. All government facilities, programs, services, and communications must be accessible, consistent with the requirements of Section 504 of the Rehabilitation Act of 1973.
- For more information on public transportation requirements, contact ADA Minnesota or the nearest regional ADA Technical Assistance Center toll-free: (800) 949-4232.
- Individuals may file complaints with federal agencies designated by the U. S. Attorney General or bring private lawsuits.

Public accommodations

- Public accommodations (such as restaurants, hotels, theaters, doctors' offices, pharmacies, retail stores, museums, libraries, parks, private schools, and day care centers) may not discriminate against people with disabilities. Private clubs and religious organizations are exempt from the law.
- Reasonable changes in policies, practices, and procedures must be made to avoid discrimination.
- Auxiliary aids and services (such as sign language interpreters, materials in Braille or large print, or assistive technology) must be provided to people with vision or hearing impairments or other disabilities so they have an equal opportunity to participate or benefit, unless doing so would cause an undue burden on the business.
- Physical barriers in existing facilities must be removed if removal is readily achievable (i.e., it can be carried out without much difficulty or expense). If not, alternative methods of providing the service must be offered, if those alternatives are readily achievable.
- All new construction in public accommodations and commercial facilities must by accessible. Elevators are generally not required in buildings under three stories or with fewer than 3000 square feet per floor, except for shopping centers, malls, or the professional offices of health care providers.
- Alterations to existing facilities must comply with ADA accessibility guidelines.
- Public accommodations may not discriminate against people or entities who have an association with individuals known to have a disability.
- Individuals may bring private lawsuits to stop discrimination, but money damages cannot be awarded. Individuals can also file complaints with the U.S. Attorney General, who may file lawsuits to stop discrimination and obtain money damages and penalties.

Telecommunications

- Companies offering telephone service to the general public must offer telephone relay services to individuals who use telecommunications devices for the deaf (TTYs) or similar devices.
- Individuals may file complaints with the Federal Communications Commission.

Books About the Americans with Disabilities Act

Gordon, Michael, Shelby Keiser, and Alta Lapoint. *Accommodations in Higher Education under the Americans with Disabilities Act. (ADA).* New York: Guilford Press 1998. Outlines how the ADA applies to a wide range of mental and physical impairments within higher education settings and explains the fundamental principles and actual clinical or administrative procedures.

Rab, Victoria Youcha, Janeen McCracken Taylor, and Darren Ikeda Wood. *Child Care and the ADA: A Handbook for Inclusive Programs.* New York: Paul H. Brookes, 1995. Beginning with a lucid explanation of the law, this revolutionary book provides step-by-step instructions for evaluating a child care center in terms of its accessibility and for developing a targeted compliance plan.

Additional Resources about Disabilities

Books for children

Brown, Tricia and Frank Ortiz. *Someone Special, Just Like You*. New York: Henry Holt, 1995. The charming text is a delightful guide intended to help preschoolers become comfortable with the children who have disabilities with whom they will go to school. (P)

Carlisle, Kim. *A Special Raccoon: Helping a Child Learn about Handicaps and Love*. Far Hills, NJ: New Horizon, 1994. Two raccoon sisters spend a beautiful spring day together where one sister learns to accept the uniqueness of her sister who has a disability. (P)

Carlson, Nancy. *Arnie and the New Kid*. New York: Puffin, 1992. No one plays with Philip because his wheelchair sets him apart. One student's temporary injury leads him to discover that Arnie and the new kids have more in common than either of them would have imagined. (P)

Caseley, Judith. *Harry and Willy and Carrothead*. New York: Greenwillow, 1991. A diverse group of boys don't let physical differences get in the way of their friendship. Though Harry was born with no left hand, it is red-headed Oscar who is teased for being different. (P, M)

Cutler, Jane. *Spaceman*. New York: Puffin, 1999. Gary tends to space out in class whenever he's having a difficult time. He is then placed in a class where different learning styles are appreciated and begins to make friends and discover that he does indeed have strengths. (M, U)

Exley, Helen, ed. *What It's Like to Be Me*. New York: Friendship, 1989. In words and drawings, children and teenagers who have disabilities share their thoughts and feelings. The contributors make their point that they do not want to be judged on the basis of their disability, but rather be accepted for whom they are. (M, U)

Fox, Mem. *Whoever You Are*. San Diego: Harcourt Brace, 1997. All over the world there are children who may not look the same or speak the same as you do, but they are all laughing and crying, eating and sleeping, and doing the same things you are. This is a beautiful tale that emphasizes that on the inside, we are all the same. (P)

Glenn, Alan C. *Teens with Physical Disabilities: Real-Life Stories of Meeting the Challenges*. Berkeley Heights, NJ: Enslow, 1995. Teenagers who have disabilities discuss the ups and downs of daily life. (U)

Kraus, Robert. *Leo, the Late Bloomer*. New York: HarperCollins, 1994. Leo, a tiger, was out of place until he finally bloomed. (P, M)

Meyer, Donald and Patricia Vadasy. *Living with a Brother or Sister with Special Needs: A Book for Sibs*. Seattle: University of Washington, 1996. Many questions that siblings of a person with disability ask are addressed in this easy-to-understand book. (M, U)

Ostrow, Vivian and William Ostrow. *All About Asthma*. Niles, IL: Albert Whitman, 1993. A boy describes his everyday life as he deals with asthma. He explains the causes and symptoms and suggests ways to get control of asthmatic episodes. (M, U)

Philbrick, Rodman. *Freak the Mighty*. New York: Scholastic, 1998. Children may be familiar with the movie based on this novel about a child who is unusually large for his age who has a learning disability and his friendship with another boy of brilliant mind and short stature. The two combine their talents to become Freak the Mighty. (M, U)

Quinsey, Mary Beth. *Why Does that Man Have Such a Big Nose?* Seattle: Parenting Press, 1986. Although this book presents text about and photographs of persons who are different, but not necessarily disabled, this guide will help parents and teachers to stimulate positive discussion about differences, emphasizing different doesn't equal bad or wrong. (P, M)

Senisi, Ellen. *Just Kids: Visiting a Class for Children with Special Needs*. New York: Dutton, 1998. Based on a true story, through intimate photos and text, this book takes a look into a special-needs classroom after a child spends time in the classroom as a result from teasing another child. This book allows children to learn that a special-needs classroom is not all that different from one of their own. (M, U)

Thompson, Mary. *My Brother, Matthew*. Bethesda, MD: Woodbine, 1992. This wonderful book filled with watercolor pictures helps portray the feelings of loneliness, rejection, and impatience of a sibling of a child with a disability while still conveying a positive outlook. (P, M)

Westwood Young Writers Workshop. *Kids Explore the Gifts of Children with Special Needs*. San Francisco: John Muir, 1994. Ten fourth- to twelfth-graders with disabilities were profiled by third- to sixth-graders for a school project. The students interviewed give candid accounts of life with their disability, including their hopes nad dreams for the future, giving major focus to what is possible. This resource is excellent for encouraging children to learn more about their classmates who have disabilities. (M, U)

Wolff, Virginia E. *Probably Still Nick Swansen: A Novel*. New York: Scholastic, 1997. This is a compassionate story about sixteen-year-old Nick, who has learning disabilities, and his struggles to endure a life in which the other kids make fun of him. He has to take special classes, his date for the prom makes an excuse not to go with him, and he is haunted by the memory of his older sister who drowned while he was watching. (U)

Books for adults

Anderson, Robert C., ed. *A Look Back: The Birth of the Americans with Disabilities Act*. New York: Haworth Pastoral Press, 1996.

Anderson, Winifred, Stephen Chitwood, and Deidre Hayden. *Negotiating the Special Education Maze: A Guide for Parents and Teachers*. Bethesda, MD: Woodbine, 1997. This is a concise guide to special education that is highly readable. This book will be useful for anyone concerned with the education of young children.

Gill, Barbara. *Changed By a Child: Companion Notes for Parents of a Child with a Disability*. New York: Doubleday, 1998. This book traces the stages of the family experience of disability, including the frustration with bureaucratic red tape, the anxiety of other pregnancies, the meaning of community and the importance of interdependence, the author's stories convey that as children grow, parents grow, and that while parents teach their children about life, children are also often the teachers.

Greenspan, Stanley, Serena Wieder and Robin Simons. *The Child with Special Needs*. New York: Perseus, 1998. This guide for parents of children with special needs is a compilation of research by Stanley Greenspan and nationally recognized child psychologist Serena Wieder. This describes a complete, step-by-step approach for parents, educators, and others who work with populations with special needs, including autism, PDD, language and speech problems, Down syndrome, cerebral palsy, and ADD. The authors offer specific interventions to assist children in expanding their intellectual and emotional possibilities.

Levine, Melvin. *All Kinds of Minds*. Educators Publishing Service, 1992. This book is written from the perspective of 5 elementary students who share a class at their neighborhood school. Written with honesty, students come to terms with their disabilities, including ADD, dyslexia, language disorder, social or motor skills, yet also discover the unique strengths inherent to them.

Marsh, Jayne. *From the Heart*. Bethesda, MD: Woodbine, 1995. This book tells the stories of nine mothers who have children with disabilities, including autism, Down syndrome, and ADD. The mothers reflect on issues such as relationships with professionals, family life, work, school issues, and feelings about themselves and their closest friends and family. The earnest stories allow us to see what is most important and most difficult for these families.

Meyer, Donald. *Uncommon Fathers*. Bethesda, MD: Woodbine, 1995. Nineteen fathers talk about the life-altering experience of having a child with disabilities and offer a refreshing perspective on raising kids with autism, cerebral palsy, and Down syndrome. This is the first book for fathers by fathers, but it is also helpful to partners, family, friends, and service providers.

Miller, Nancy, and Catherine Sammons. *Everybody's Different: Understanding and Changing our Reactions to Disabilities*. Baltimore: Paul H. Brooks, 1999. This comprehensive guide explores how to improve interactions between students with disabilities and those without. Focusing on specific disabilities, attitudes about disabilities, as well as common stereotypes, are explored.

Stainback, Susan, and William Stainback. *Inclusion: A Guide for Educators*. Baltimore: Paul H. Brooks, 1996. This is an excellent guide for teachers describing techniques and specific strategies that teachers may use to support kids with disabilities in the classroom. The authors offer proven methods for addressing behavior and learning problems and achieving positive results in the classroom.

Staub, Debbie. *Delicate Threads: Friendships Between Children with and without Special Needs in Inclusive Settings*. Bethesda, MD: Woodbine, 1998. This book is a compilation of careful observations of friendships between seven pairs of children—each including a child with a moderate to severe disability—who are classmates in an inclusive Pacific Northwest elementary school. This book provides important, real-life confirmation about the merits of inclusion, as well as practical suggestions for teachers and parents.

Stengle, Linda. *Laying Community Foundations for Your Child with a Disability*. Bethesda, MD: Woodbine, 1996. This practical step-by-step guide assists families of children with special needs how to establish a network of non-paid people to provide lasting relationships for their child. Although financial planning is important, this book is an excellent reminder that there is much more to consider.

Sweeney, Wilma. *The Special-Needs Reading List: An Annotated Guide to the Best Publications for Parents & Professionals*. Bethesda, MD: Woodbine, 1998. Reviews and recommendations for the best books, journals, newsletters, organizations, and other information sources on children with disabilities—an invaluable resource.

Videos

A Little History Worth Knowing. Syracuse, NY: Program Development Associates, 1999. This candid video traces the history of persons with disabilities, including the stereotypes present in the media and the struggles for disability rights. (22 minutes)

A New Idea for Special Education. Syracuse, NY: Program Development Associates, 1999. The recent changes in the Individuals with Disabilities in Education Act (IDEA) are given a thorough examination. Offers helpful hints from parents, advice from experts in the field, plus some words of encouragement from the students themselves. Key areas covered: The New Law; The Referral Process into Special Education; The Evaluation Process of a Child; Creating an Individualized Education Plan; Placement & Related Services; Preparing for Transition; Discipline, Mediation & Standardized Testing & Referral Resources. (40 minutes)

Abandoned to Their Fate: A History of Social Policy Toward People Labeled Severely Retarded. Eugene, OR: School Projects Publications, 1997. This video discusses the origin of social policy as well as cultural stereotypes of people with severe disabilities. (30 minutes)

Able to Laugh. Boston: Fanlight, 1993. Six professional comedians, all of whom have disabilities, provide an amusing and informative glimpse into the world of special needs. (27 minutes)

Breathing Lessons: The Life and Work of Mark O'Brien. Boston: Fanlight, 1996. This video profiles the life of Mark O'Brien, a photojournalist who has spent 40 years living with an iron lung. (35 minutes)

Business As Usual. Boston: Fanlight, 1994. A video on creating opportunities for people with disabilities. (39 minutes)

The Challenge. Boston: Fanlight, 1999. People with a variety of disabilities — including blindness, mobility impairments and deafness — who are rock climbers, wheelchair tennis players, golfers, and skiers are profiled in this beautifully photographed program. (28 minutes)

Dancing From the Inside Out. Boston: Fanlight, 1996. Tells the provocative and powerfully moving stories of three extraordinary professional dancers with disabilities and their paths to self acceptance. (28 minutes)

Disability and Motherhood. Syracuse, NY: Program Development Associates, 1999. Examines the experiences of three mothers with disabilities, as well as public attitudes towards them. (25 minutes)

Disabled Women: Visions and Voices. Syracuse, NY: Program Development Associates, 1999. This documentary highlights accomplishments of the women of the First International Symposium on Issues of Women with Disabilities, the UN Fourth World Conference on Women and NGO Forum. (13 minutes)

Face First. Boston: Fanlight, 1998. The filmmaker's own painful memories of social isolation as a child with a cleft lip and palate led him to the other three remarkable people profiled. Their stark anecdotes about the physical pain of corrective procedures, coupled with the psychological sting of ridicule and rejection reflect the reality faced by those who are seen as different. Yet the film demonstrates how these experiences have also generated inner strengths they feel have made them uniquely qualified for their chosen careers in journalism, public speaking and disability care. (29 minutes)

Key Changes. Boston: Fanlight, 1993. This new documentary profiles Lisa Thorson, a gifted vocalist who uses a wheelchair. Ms. Thorson defines herself as a performer first, a person with a disability second, and this thoughtful portrait respects that distinction. Her work as a jazz singer is at the heart of the film, reflecting her philosophy that the biggest contribution that she can make to the struggle for the rights of people with disabilities "is doing (her) art the best way that (she) can." The video artfully weaves footage of Thorson's performances with interviews which allow the singer to tell her story. (28 minutes)

Kids in Wheelchairs. Syracuse, NY: Program Development Associates, 1999. Portrays the children in full inclusion settings, classrooms and playgrounds. They explain why they use the wheelchair and how the chair works. Most important, children themselves ask questions and address some of the feelings they have about children who use wheelchairs. Aspects of how to become a safe and responsible peer buddy are described. (12 minutes)

Look Who's Laughing. Syracuse, NY: Program Development Associates, 1999. A look at the lives, experiences and humor of six working comedians who have various types of disabilities. Shot at comedy clubs across the country. (56 minutes)

My Body is Not Who I Am. Aquarius Productions, 1994. A candid and thought-provoking video that uses personal testimonies to explore the struggles and triumphs of individuals living with a physical disability. (35 minutes)

My Country. Syracuse, NY: Program Development Associates, 1999. This video profiles three persons active in the fight for disability rights. Narrated by James DePriest, a symphony conductor and polio survivor. (58 minutes)

Shaking Off Stereotypes. Syracuse, NY: Program Development Associates, 1999. Will help people with disabilities and others recognize that we are all unique individuals with something to contribute. An entertaining story about a woman wheelchair user that discovers her own self-worth in spite of the everyday stereotypical situations she encounters. Includes facilitator's guide, participatory exercises, action plans, overhead masters, collection of personal histories and 10 participant's packages including: 10 participant workbooks, 24 pages each; certificates of completion; buttons; posters; postcards; and name tags. (16 minutes)

Small Differences. Syracuse, NY: Program Development Associates, 1999. Young students were given cameras and instructions on interview techniques and told to go interview fellow students with disabilities, family members, and each other. What resulted is a professionally edited, student-narrated video that encourages discussion about and inclusion of persons with disabilities.

Sticks and Stones. Syracuse, NY: Program Development Associates, 1999. An award-winning program on the origins of the self-advocacy movement in Minnesota, re-edited and perfect for the classroom or workshop. Learn about self-advocacy as activists and allies look back on their struggle for civil and human rights for people with developmental disabilities. (30 minutes)

This Is YOUR Right. Syracuse, NY: Program Development Associates, 1999. A look at where people with disabilities have been and where they want to be. Includes funny commercials about fictitious products and services that are intended to lampoon situations that people with disabilities encounter in everyday life. (60 minutes)

Twitch and Shout. Boston: Boston: Fanlight, 1998. Provides an intimate journey into the startling world of Tourette Syndrome, a genetic disorder that can cause a bizarre range of involuntary movements, vocalizations and compulsions. Introduces viewers to people who have this puzzling disorder including a professional basketball player, an artist, an actress, and a lumberjack. An emotionally absorbing, sometimes unsettling and finally uplifting program about people who must contend with a society that often sees them as crazy or bad — and a body and mind that won't always do what they are told. (57 minutes)

Vital Signs: Crip Culture Talks Back. Boston: Boston: Fanlight, 1997. This documentary looks at disability rights from the perspective of performance artists and activists in order to examine the culture of disability. *Contains strong language and nudity.* (48 minutes)

Waddie Welcome. Syracuse, NY: Program Development Associates, 1999. The many fascinating stories, the heartbreak, and the triumphs experienced by Welcome are presented by his circle of friends, who listened to his pleas, learned to communicate in his language, and used person-centered planning to enable him to live with a family after a 10-year stay in nursing homes. Documents the power of person-centered planning, the success of supported living, and the advocacy needed to support persons with disabilities. A challenge to redesign the responsiveness of community service systems. (26 minutes)

When Billy Broke His Head. Boston: Boston: Fanlight, 1994. Billy Golfus, a journalist who became brain-injured in a motor scooter accident, goes on the road in a cheeky and amusing mission to investigate the conception and development of the disability rights movement. (57 minutes)

When Parents Can't Fix It. Boston: Fanlight, 1997. Looks at the lives of five families who are raising children with disabilities – the problems they face, how they have learned to cope, and the rewards and stresses of adapting to their children's condition. It explores the medical complexities and financial pressures families encounter, the emotional and physical toll on parents & siblings, and the dangers of child abuse in this population. It offers a realistic look at different family strengths and coping styles, and highlights the way society can help meet the needs of families with disabled children. (58 minutes)

Without Pity: A Film about Disabilities. Syracuse, NY: Program Development Associates, 1999. This HBO documentary narrated by Christopher Reeve focuses on the determination of persons with disabilities to lead self-sufficient, productive lives. The viewer meets many individuals who have disabilities leading the lives some would never have thought possible for them. (52 minutes)

Your Choice, My Decision. Syracuse, NY: Program Development Associates, 1999. Illustrates the often-hilarious differences between new fads in providing services to people with disabilities and what people really want for themselves. Uncovers our most basic prejudices and common mistakes. (30 minutes)

Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs)

The addresses and phone numbers for Parent Training and Information Centers and Community Parent Resource Centers below are current through June 1, 2001. For more recent contact information, call PACER Center at (952) 838-9000 Voice or (952) 838-0190 TTY.

ALABAMA

Special Education Action Committee Inc.
P.O. Box 161274Mobile, AL 36616-2274
334-478-1208 voice & TDD
334-473-7877 fax
1-800-222-7322 AL only
seacofmobile@zebra.net
home.hiwaay.net/~seachsv

ALASKA

PARENTS, Inc.
4743 E. Northern Lights Blvd
Anchorage, AK 99508
907-337-7678 voice
907-337-7629 TDD
907-337-7671 fax
1-800-478-7678 in AK
parents@parentsinc.org
www.parentsinc.org

AMERICAN SAMOA

American Samoa PAVE
P.O. Box 6844
Pago Pago, AS 96799
011-684-699-6946
011-684-699-6952 fax
SAMPAVE@samoatelco.com
www.taalliance.org/ptis/amsamoa

ARIZONA

Pilot Parents of Southern Arizona
2600 North Wyatt Drive
Tucson, AZ 85712
520-324-3150
520-324-3152
ppsa@pilotparents.org
www.pilotparents.org
Southern AZ

RAISING Special Kids
4750 N. Black Canyon Hwy, Ste. 101
Phoenix, AZ 85017-3621
602-242-4366 voice & TDD
602-242-4306 fax
1-800-237-3007 in AZ
raisingspecialk1@qwest.net
Central and Northern AZ

ARKANSAS

Arkansas Disability Coalition
1123 University Ave., Ste. 225
Little Rock, AR 72204-1605
501-614-7020 voice & TDD
501-614-9082 fax
1-800-223-1330 AR only
adc@alltel.net
www.adcpti.org
Statewide with FOCUS AR

FOCUS, Inc.
305 West Jefferson Ave.
Jonesboro, AR 72401
870-935-2750 voice
870-931-3755 fax
888-247-3755
focusinc@ipa.net
www.grnco.net/~norre
With Arkansas Disability Coalition AR

CALIFORNIA

DREDF
2212 Sixth St.
Berkeley, CA 94710
510-644-2555 (TDD available)
510-841-8645 fax
1-800-466-4232
dredf@dredf.org
www.dredf.org
Northern California with Parents Helping Parents, Santa Clara

Exceptional Family Support, Education and Advocacy Center
6402 Skyway
Paradise, CA 95969
530-876-8321
530-876-0346
1-888-263-1311
sea@sunset.net
www.sea-center.org

Exceptional Parents Unlimited
4440 N. First St.
Fresno, CA 93726
559-229-2000
559-229-2956 fax
epu1@cybergate.com
www.exceptionalparents.org
Central California

Loving Your Disabled Child (CPRC)
4528 Crenshaw Blvd.
Los Angeles, CA 90043
323-299-2925
323-299-4373 fax
lydc@pacbell.net
www.lydc.org
Most of LA County

Matrix
94 Galli Drive, Ste. C
Novato, CA 94949
415-884-3535
415-884-3555 fax
1-800-578-2592
alliance@matrixparents.org
www.matrixparents.org
Northern California with Parents Helping Parents, Santa Clara

Parents Helping Parents of San Francisco
594 Monterey Blvd.
San Francisco, CA 94127-2416
415-841-8820
415-841-8824 fax
sfphp@earthlink.com
Nine counties in the
San Francisco Bay area

Parents Helping Parents of Santa Clara
3041 Olcott St.
Santa Clara, CA 95054-3222
408-727-5775 voice / 408-727-7655 TDD
408-727-0182 fax
info@php.com
www.php.com
Northern California with Matrix and DREDF

Parents of Watts (CPRC)
10828 Lou Dillon Ave.
Los Angeles, CA 90059
323-566-7556
323-569-3982 fax
egertonf@hotmail.com
With Loving Your Disabled Child

Support for Families of Children with Disabilities
2601 Mission #710
San Francisco, CA 94110-3111
415-282-7494
415-282-1226 fax
sfcdmiss@aol.com
San Francisco

TASK
100 West Cerritos Ave.
Anaheim, CA 92805
714-533-8275
714-533-2533 fax
taskca@aol.com
Southern California

TASK, San Diego
3750 Convoy St., Ste. 303
San Diego, CA 92111-3741
858-874-2386
858-874-2375 fax
tasksd1@aol.com
City of San Diego and Imperial counties

Vietnamese Parents of Disabled Children Assoc., Inc. (CPRC)
7526 Syracuse Ave.
Stanton, CA 90680
310-370-6704
310-542-0522 fax
luyenchu@aol.com
With Loving Your Disabled Child

COLORADO

PEAK Parent Center, Inc.
611 North Weber, Ste. 200
Colorado Springs, CO 80903
719-531-9400 voice / 719-531-9403 TDD
719-531-9452 fax
1-800-284-0251
info@peakparent.org
www.peakparent.org

CONNECTICUT

Connecticut Parent Advocacy Center
338 Main St.
Niantic, CT. 06357
860-739-3089 voice & TDD
860-739-7460 fax *(Call first to dedicate line)*
1-800-445-2722 in CT
cpac@cpacinc.org
www.cpac.org

DELAWARE

Parent Information Center of Delaware (PIC/DE)
700 Barksdale Road, Ste. 16
Newark, DE 19711
302-366-0152 voice / 302-366-0178 (TDD)
302-366-0276 fax
1-888-547-4412
picofdel@picofdel.org
www.picofdel.org

DISTRICT OF COLUMBIA

Advocates for Justice and Education
2041 Martin Luther King Ave., SE
Ste. 301
Washington, DC 20020
202-678-8060
202-678-8062 fax
1-888-327-8060
justice1@bellatlantic.net
www.aje.qpg.com/

FLORIDA

Family Network on Disabilities
2735 Whitney Road
Clearwater, FL 33760-1610
727-523-1130
727-523-8687 fax
1-800-825-5736 FL only
fnd@fndfl.org
www.fndfl.org

Parent to Parent of Miami, Inc. (CPRC)
c/o Sunrise Community
9040 Sunset Drive, Ste. G
Miami, FL 33173
305-271-9797
305-271-6628 fax
PtoP1086@aol.com
Miami Dade and Monroe Counties

GEORGIA

Parents Educating Parents and Professionals for All Children (PEPPAC)
6613 East Church St., Ste. 100
Douglasville, GA 30134
770-577-7771
770-577-7774 fax
peppac@bellsouth.net
www.peppac.org

HAWAII

AWARE
200 N. Vineyard Blvd., Ste. 310
Honolulu, HI 96817
808-536-9684 voice
808-536-2280 voice & TTY
808-537-6780 fax
1-800-533-9684
ldah@gte.net

Palau Parent Network
Center on Disability Studies,
University of Hawaii
1833 Kala Kaua Ave., #609
Honolulu, HI 96815
808-945-1432
808-945-1440 fax
dotty@hawaii.edu
patric@palaunet.com

IDAHO

Idaho Parents Unlimited, Inc.
4696 Overland Road, Ste. 568
Boise, ID 83705
208-342-5884 voice & TDD
208-342-1408 fax
1-800-242-4785
ipul@rmci.net
home.rmci.net/ipul

Native American Parent Training and Information Center
129 East Third
Moscow, ID 83843
208-885-3500
208-885-3628 fax
famtog@moscow.com
Nation-wide resource for Native American families, tribes, and communities as well as parent centers and others needing information on this subject.

ILLINOIS

Designs for Change
29 East Madison, Ste. 95
Chicago, IL 60602
312-236-7252 voice / 312-857-1013 TDD
312-236-7927 fax
markse@designsforchange.org
www.dfc1.org

Family Resource Center on Disabilities
20 E. Jackson Blvd., Room 300
Chicago, IL 60604
312-939-3513 voice
312-939-3519 TTY & TDY
312-939-7297 fax
1-800-952-4199 IL only
frcdptiil@ameritech.net
www.ameritech.net/users/frcdptiil/index

Family Resource Center on Disabilities
20 E. Jackson Blvd., Room 300
Chicago, IL 60604
312-939-3513 voice
312-939-3519 TTY & TDY
312-939-7297 fax
1-800-952-4199 IL only
frcdptiil@ameritech.net
www.ameritech.net/users/frcdptiil/index

Family T.I.E.S. Network
830 South Spring
Springfield, IL 62704
217-544-5809
217-544-6018 fax
1-800-865-7842
mrsinclusion@aol.com
www.taalliance.org/ptis/fties

National Center for Latinos with Disabilities
1915-17 South Blue Island Ave.
Chicago, IL 60608
312-666-3393 voice / 312-666-1788 TTY
312-666-1787 fax
1-800-532-3393
ncld@ncld.com
homepage.interaccess.com/~ncld

INDIANA

IN*SOURCE
809 N. Michigan St.
South Bend, IN 46601-1036
219-234-7101
219-239-7275 TDD
219-234-7279 fax
1-800-332-4433 in IN
insourc1@aol.com
www.insource.org

IOWA

Access for Special Kids (ASK)
321 E. 6th St.
Des Moines, IA 50309
515-243-1713
515-243-1902 fax
1-800-450-8667
ptiiowa@aol.com
www.taalliance.org/ptis/ia

KANSAS

Families ACT (CPRC)
Nina Lomely-Baker
555 N. Woodlawn
Wichita, KS 67203
316-685-1821
316-685-0768 fax
nina@mhasck.org
www.mhasck.org
Sedgwick County and outlying area

Families Together, Inc.
3340 W Douglas, Ste. 102
Wichita, KS 67203
316-945-7747
316-945-7795 fax
1-888-815-6364
fmin@southwind.net
www.familiestogetherinc.com

KENTUCKY

FIND of Louisville (CPRC)
1146 South Third St.
Louisville, KY 40203
502-584-1239
502-584-1261 fax
info@council-crc.org
www.council-crc.org

Kentucky Special Parent Involvement Network (SPIN)
10301 B Deering Road
Louisville, KY 40272
502-937-6894
502-937-6464 fax
1-800-525-7746
spininc@aol.com

LOUISIANA

Pyramid Parent Training Program (CPRC)
4101 Fontainbleau Dr.
New Orleans, LA 70125
504-827-0610
504-827-2999 fax
dmarkey404@aol.com

Project PROMPT
4323 Division Street, Ste. 110
Metairie, LA 70002-3179
504-888-9111
504-888-0246 fax
1-800-766-7736
fhfgno@ix.netcom.com
www.projectprompt.com

MAINE

Special Needs Parent Info Network
P.O. Box 2067
Augusta, ME 04338-2067
207-623-2144
207-623-2148 fax
1-800-870-7746
jlachance@mpf.org
www.mpf.org

MARYLAND

Parents Place of Maryland, Inc.
7484 Candlewood Rd. Ste. S
Hanover, MD 21076-1306
410-859-5300 voice & TDD
410-859-5301 fax
info@ppmd.org
www.ppmd.org

MASSACHUSETTS

Federation for Children with Special Needs
1135 Tremont St., Ste. 420
Boston, MA 02120-2140
617-236-7210 (voice and TTY)
617-572-2094 fax
1-800-331-0688 in MA
fcsninfo@fcsn.org
www.fcsn.org

Urban / PRIDE (CPRC)
1472 Tremont
Roxbury Crossing, MA 02120
617-445-3191
617-445-6309 fax
1-800-331-0688 in MA
cspinkstion@compassinc.com

IPEST (CPRC)
P.O. Box 4081
Vineyard Haven, MA 02568
508-696-5486
508-696-5497 fax
ckennedy@fastdial.net

MICHIGAN

CAUSE
3303 W. Saginaw, Ste. F-1
Lansing, MI 48917-2303
517-886-9167 voice & TDD & TDY
517-886-9775 fax
1-800-221-9105 in MI
info@causeonline.org
www.causeonline.org

"Parents are Experts" Parents Training Parents
23077 Greenfield Road, Ste. 205
Southfield, MI 48075-3745
248-557-5070 voice & TDD
248-557-4456 fax
1-800-827-4843
ucp@ameritech.net
www.taalliance.org/ptis/mi-parents
Wayne County
406-255-0523 fax
1-800-222-7585 in MT
plukinfo@pluk.org
www.pluk.org

NEBRASKA

Nebraska Parents Center
1941 South 42nd St., #122
Omaha, NE 68105-2942
402-346-0525 voice & TDD
402-346-5253 fax
1-800-284-8520
gdavis@neparentcenter.org
www.neparentcenter.org
617-445-6309 fax
1-800-331-0688 in MA
cspinkstion@compassinc.com

NEVADA

Nevada Parents Encouraging Parents (PEP)
2810 W. Charleston Blvd., Ste. G-68
Quail Park IV
Las Vegas, NV 89102
702-388-8899
702-388-2966 fax
1-800-216-5188
nvpep@vegas.infi.net
www.nvpep.org

NEW HAMPSHIRE

Parent Information Center
P.O. Box 2405
Concord, NH 03302-2405
603-224-7005 (voice & TDD)
603-224-4379 fax
1-800-232-0986 in NH
picnh@aol.com
www.parentinformationcenter.org

NEW JERSEY

Statewide Parent Advocacy Network (SPAN)
35 Halsey Street, 4th Floor
Newark, NJ 07102
973-642-8100
973-642-8080 fax
1-800-654-SPAN
span@spannj.org
www.spannj.org

NEW MEXICO

Parents Reaching Out, Project ADOBE
1000-A Main St. NW
Los Lunas, NM 87031
505-865-3700 voice & TDD
505-865-3737 fax
1-800-524-5176 in NM
nmproth@aol.com
www.parentsreachingout.org

EPICS Project (CPRC)
412 Camino Don Thomas, P.O. Box 788
Bernalillo, NM 87004-0788
505-867-3396
505-867-3398 fax
1-800-524-5176 in NM
epics@swcr.org

NEW YORK

The Advocacy Center
277 Alexander St., Ste. 500
Rochester, NY 14607
716-546-1700
716-546-7069 fax
1-800-650-4967 (NY only)
advocacy@frontiernet.net
www.advocacycenter.com
Statewide except for NY City

Advocates for Children of NY
151 West 30th St., 5th Floor
New York, NY 10001
212-947-9779
212-947-9790 fax
aespada@advocatesforchildren.org
www.advocatesforchildren.org
Five boroughs of New York City

Resources for Children with Special Needs, Inc.
200 Park Ave. South, Ste. 816
New York, NY 10003
212-677-4650
212-254-4070 fax
info@resourcesnyc.org
www.resourcesnyc.org
New York City (Bronx, Brooklyn, Manhattan, Queens, Staten Island)

Sinergia/Metropolitan Parent Center
15 West 65th St., 6th Floor
New York, NY 10023
212-496-1300
212-496-5608 fax
dalsinergia@worldnet.att.net
www.sinergiany.org
New York City

United We Stand (CPRC)
312 South 3rd St.
Brooklyn, NY 11211
718-302-4313
718-302-4315 fax
uwsofny@aol.com
www.taalliance.org/ptis/uws

NORTH CAROLINA

ECAC, Inc.
P.O. Box 16
Davidson, NC 28036
704-892-1321
704-892-5028 fax
1-800-962-6817 NC only
ECAC1@aol.com
www.ecac-parentcenter.org

NORTH DAKOTA

ND Pathfinder Parent Training And Information Center
Arrowhead Shopping Center
1600 2nd Ave. SW, Ste. 19
Minot, ND 58701-3459
701-837-7500 voice / 701-837-7501 TDD
701-837-7548 fax
1-800-245-5840 ND only
ndpath01@minot.ndak.net
www.pathfinder.minot.com

OHIO

Child Advocacy Center
1821 Summit Road, Ste. 303
Cincinnati, OH 45237
513-821-2400
513-821-2442 fax
CADCenter@aol.com
Southwestern Ohio, Northern Kentucky, Dearborn County, Indiana

OCECD
Bank One Building
165 West Center St., Ste. 302
Marion, OH 43302-3741
740-382-5452 voice & TDD
740-383-6421 fax
1-800-374-2806
ocecd@gte.net
www.taalliance.org/PTIs/regohio

OKLAHOMA

Oklahoma Parents Center, Inc.
4600 Southeast 29th St., Ste. 115
Del City, OK 73115-4224
405-619-0500
405-670-0776 fax
1-800-759-4142
okparentctr@aol.com
www.taalliance.org/ptis/ok

OREGON

Oregon COPE Project
999 Locust St. NE
Salem, OR 97303
503-581-8156 voice & TDD
503-391-0429 fax
1-888-505-COPE
orcope@open.org
www.open.org/~orcope

PENNSYLVANIA

Hispanos Unidos para Niños Excepcionales (Hispanics United for Exceptional Children) (CPRC)
Buena Vista Plaza
166 W. Lehigh Ave., Ste. 101
Philadelphia, PA 19133-3838
215-425-6203
215-425-6204 fax
huneinc@aol.com
City of Philadelphia, occasional service to
surrounding counties

Parent Education Network
2107 Industrial Hwy.
York, PA 17402-2223
717-600-0100 voice & TTY
717-600-8101 fax
1-800-522-5827 in PA
1-800-441-5028 (Spanish in PA)
pen@parentednet.org
www.parentednet.org

The Mentor Parent Program (CPRC)
P.O. Box 47
Pittsfield, PA 16340
814-563-3470
814-563-3445 fax
swalder@westpa.net

PUERTO RICO

APNI
P.O. Box 21280
Ponce de Leon 724
San Juan, PR 00928-1280
787-763-4665
787-765-0345 fax
1-800-981-8492
apnipr@prtc.net
Island of Puerto Rico

RHODE ISLAND

RI Parent Information Network
175 Main St.
Pawtucket, RI 02860
401-727-4144 voice / 401-727-4151 TDD
401-727-4040 fax
1-800-464-3399 in RI
collins@ripin.org
http://www.ripin.org

SOUTH CAROLINA

Parent Training & Resource Center (CPRC)
c/o Family Resource Center
135 Rutledge Ave., P.O. Box 250567
Charleston, SC 29425
843-876-1519
843-876-1518 fax
mccarthyb@musc.edu
Tri-county: Charleston, Berkeley, and Dorchester

PRO-PARENTS
2712 Middleburg Drive, Ste. 203
Columbia, SC 29204
803-779-3859 voice
803-252-4513 fax
1-800-759-4776 in SC
proparents@aol.com
www.proparents.org

SOUTH DAKOTA

South Dakota Parent Connection
3701 West 49th St., Ste. 200B
Sioux Falls, SD 57106
605-361-3171 voice & TDD
605-361-2928 fax
1-800-640-4553 in SD
bpete@dakota.net
www.sdparent.org

TENNESSEE

Support and Training for Exceptional Parents, Inc. (STEP)
424 E. Bernard Ave., Ste. 3
Greeneville, TN 37745
423-639-0125 voice / 636-8217 TDD
423-636-8217 fax
1-800-280-STEP in TN
tnstep@aol.com
www.tnstep.org

TEXAS

El Valle Community Parent Resource Center (CPRC)
530 South Texas Blvd., Ste. J
Weslaco, TX 78596
956-969-3611
956-969-8761 fax
1-800-680-0255 TX only
texasfiestaedu@acnet.net
www.tfepoder.org
Cameron, Willacy, & Starr Counties.

The Arc of Texas in the Rio Grande Valley Parents Supporting Parents Network (CPRC)
601 N Texas Blvd.
Weslaco, TX 78596
956-447-8408

Project PODER
1017 N. Main Ave., Ste. 207
San Antonio, TX 78212
210-222-2637
210-475-9283 fax
1-800-682-9747 TX only
poder@tfepoder.org
www.tfepoder.org
San Antonio, Hondo, & Castroville, Cameron, Hidalgo, Willacy, & Starr Counties.

UTAH

Utah Parent Center
2290 East 4500 S., Ste. 110
Salt Lake City, UT 84117-4428
801-272-1051
801-272-8907 fax
1-800-468-1160 in UT
helenpo@utahparentcenter.org
www.utahparentcenter.org

VERMONT

Vermont Parent Information Center
1 Mill Street, Ste. A7
Burlington, VT 05401
802-658-5315 voice & TDD
802-658-5395 fax
1-800-639-7170 in VT
vpic@together.net
www.vtpic.com

VIRGIN ISLANDS

V.I. FIND
#2 Nye Gade
St. Thomas, US VI 00802
340-774-1662
340-774-1662 fax
vifind@islands.vi
www.taalliance.org/ptis/vifind
956-973-9503 fax
1-888-857-8688
ljzuniga@earthlink.net
www.thearcoftexas.org

Partners Resource Network Inc.
1090 Longfellow Drive, Ste. B
Beaumont, TX 77706-4819
409-898-4684 voice & TDD
409-898-4869 fax
1-800-866-4726 in TX
txprn@pnx.com
www.PartnersTX.org

VIRGINIA

PADDA, Inc. (CPRC)
813 Forrest Drive, Ste. 3
Newport News, VA 23606
757-591-9119
757-591-8990 fax
1-888-337-2332
webmaster@padda.org
www.padda.org

Parent Educational Advocacy Training Center
6320 Augusta Drive
Springfield, VA 22150
703-923-0010
703-923-0030 fax
1-800-869-6782 VA only
partners@peatc.org
www.peatc.org

WASHINGTON

Parent to Parent Power (CPRC)
1118 S 142nd St.
Tacoma, WA 98444
253-531-2022
253-538-1126 fax
yvonne_link@yahoo.com

PAVE/STOMP
6316 South 12th St., Ste. B
Tacoma, WA 98465
253-565-2266 voice & TTY
253-566-8052 fax
1-800-572-7368
hhebdon@washingtonpave.com
www.washingtonpave.org
U.S. military installations: and parent centers and others needing information on this subject.

PAVE
6316 South 12th St., Ste. B
Tacoma, WA 98465-1900
253-565-2266 (voice & TDD)
253-566-8052 fax
1-800-572-7368 in WA
jbutts@washingtonpave.com
www.washingtonpave.org

WEST VIRGINIA

West Virginia PTI
Pat Haberbosch
371 Broaddus Ave.
Clarksburg, WV 26301
304-624-1436 voice & TTY
304-624-1438
1-800-281-1436 in WV
wvpti@aol.com
www.wvpti.org

WISCONSIN

Native American Family Empowerment Center
Great Lakes Inter-Tribal Council, Inc.
2932 Hwy. 47N, P.O. Box 9
Lac du Flambeau, WI 54538
715-588-3324
715-588-7900
1-800-472-7207 (WI only)
drosin@newnorth.net

Parent Education Project of Wisconsin
2192 South 60th St.
West Allis, WI 53219-1568
414-328-5520 voice / 414-328-5525 TDD
414-328-5530
1-800-231-8382 (WI only)
PMColletti@aol.com
members.aol.com/pepofwi

Wisconsin Family Assistance Center for Education, Training and Support (CPRC)
2714 North Dr. Martin Luther King Dr., Ste. E
Milwaukee, WI 53212
414-374-4645 / 414-374-4635 TTD
414-374-4655 fax
wifacets@execpc.com

WYOMING

Parent Information Center
5 North Lobban
Buffalo, WY 82834
307-684-2277 voice & TDD
307-684-5314
1-800-281-1436 in WY
tdawson@wpic.org

PACER CENTER

www.pacer.org